Chronic Diseases in Canada

Volume 29 · Number 1 · 2008

Inside this issue

1 **Health Literacy and Numeracy: Key Factors in Cancer Risk Comprehension**
L Donelle, JF Arocha, L Hoffman-Goetz

9 **Colorectal Cancer Screening in Canada: Results of a National Survey**
MJ Sewitch, C Fournier, A Ciampi, A Dyachenko

22 **Stroke Surveillance in Manitoba, Canada: Estimates from Administrative Databases**
DF Moore, LM Lix, MS Yogendran, P Martens, A Tamayo

31 **Population-Based Data Sources for Chronic Disease Surveillance**
LM Lix, MS Yogendran, SY Shaw, C Burchill, C Metge, R Bond

39 **The Second National Sun Survey: Workshop Report**
Bronwen Waller, Erin Pichora, Loraine Marrett

43 **Announcements**

Public Health Agency of Canada
Agence de la santé publique du Canada

Canada

Public Health Agency of Canada | Agence de la santé publique du Canada

Canada

ARE YOU ON TOP OF CHRONIC DISEASE PREVENTION RESEARCH?

Chronic Diseases in Canada:
Research. Intervention. Prevention.

The Public Health Agency's peer-reviewed journal.

Subscribe today! Submit your manuscripts!

Special: Call for papers on chronic disease intervention research.
cdic-mcc@phac-aspc.gc.ca

www.publichealth.gc.ca/cdic

Chronic Diseases in Canada
a publication of the Public Health Agency of Canada

Sylvie Stachenko
Principal Scientific Editor
(613) 946-3537

Howard Morrison
Deputy Scientific Editor
(613) 941-1286

Robert A Spasoff
Associate Scientific Editor

Claire Infante-Rivard
Associate Scientific Editor

Elizabeth Kristjansson
Associate Scientific Editor

Michelle Tracy
Managing Editor
(613) 954-0697

CDIC Editorial Board

Jacques Brisson
Laval University

Neil E Collishaw
Physicians for a Smoke-Free Canada

James A Hanley
McGill University

Clyde Hertzman
University of British Columbia

C Ineke Neutel
University of Ottawa
Institute on Care of the Elderly5

Kathryn Wilkins
Health Statistics Division
Statistics Canada

Chronic Diseases in Canada (CDIC) is a quarterly scientific journal focussing on current evidence relevant to the control and prevention of chronic (i.e. non-communicable) diseases and injuries in Canada. Since 1980 the journal has published a unique blend of peer-reviewed feature articles by authors from the public and private sectors and which may include research from such fields as epidemiology, public/community health, biostatistics, the behavioural sciences, and health services or ecoZnomics. Only feature articles are peer reviewed. Authors retain responsibility for the content of their articles; the opinions expressed are not necessarily those of the CDIC editorial committee nor of the Public Health Agency of Canada.

Chronic Diseases in Canada
Public Health Agency of Canada
130 Colonnade Road
Address Locator 6501A
Ottawa, Ontario K1A 0K9

Fax: (613) 941-3605
E-mail: cdic-mcc@phac-aspc.gc.ca

Indexed in Index Medicus/MEDLINE

To promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.
— Public Health Agency of Canada

Published by authority of the Minister of Health.
© Her Majesty the Queen in Right of Canada, represented by the Minister of Health, 2008
ISSN 0228-8699

This publication is also available online at www.publichealth.gc.ca/cdic
Également disponible en français sous le titre : *Maladies chroniques au Canada*

Health literacy and numeracy: Key factors in cancer risk comprehension

L Donelle, RN, PhD (1); J. F. Arocha, PhD (2); L Hoffman-Goetz, PhD, MPH (2)

Abstract

In this age of chronic disease and shared decision making, individuals are encouraged to contribute to decisions about health care. Health literacy, including numeracy, is requisite to meaningful participation and has been accepted as a determinant of health. The purpose of this study was to describe the influence of literacy, consisting of prose and numeracy skill, math anxiety, attained education and context of information on participant ability to comprehend Internet-based colorectal cancer prevention information. Prose, numeracy, and math-anxiety data, as well as demographic details, were collected for 140 Canadian adults, aged 50+ years. Participants had adequate prose literacy (STOFHLA) scores, high STOFHLA numeracy scores, moderate levels of health-context numeracy, poorer general-context numeracy and moderate math anxiety. There was better comprehension by participants of common (9.14/11) compared with uncommon (7.64/11) colorectal cancer information ($p < 0.01$). Prose literacy, numeracy, math anxiety and attained education accounted for 60% of the variation in participant comprehension scores. Numeracy, ranging from basic to advanced proficiency, is required to understand online cancer risk information. Prose literacy enhances numeracy when the subject matter is less familiar. These findings highlight the importance of presenting Web-based information that accommodates diverse health literacy and numeracy levels.

Key words: *communication, risk, Internet, neoplasms, health literacy, numeracy*

Introduction

Health literacy is essential to understanding health information and is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[1] Furthermore, the Public Health Agency of Canada identifies literacy as an important determinant of health.[2] Yet, many adults are limited in prose health literacy and health numeracy skill. In particular, more older than younger adults demonstrate poor literacy skills.[3-14] Estimates of inadequate or marginal health literacy among seniors range from 34% of individuals aged 65 years and older[4,7,14] to 81% of individuals 60 years and older.[11] Inadequate health literacy skill has been identified as an important barrier for seniors to understand diagnoses and treatment protocols.[3,11]

Until recently, health literacy has been portrayed mainly as a reading comprehension skill with health numeracy attracting little research attention.[10] Health numeracy is "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical and probabilistic health information needed to make effective health decisions."[10] Published accounts of numeric competency within health care settings indicate inadequate numeracy skills among young[9,15,16] and older adults.[12,16] Cancer patients with decreased numeracy skills may have a diminished ability to accurately assess and personalize health risks.[10,17,20]

Colorectal cancer is the fourth leading cause of cancer among Canadians and the second leading cause of cancer deaths.[21] Further increases in incident colorectal cancers are anticipated resultant to an aging population.[21] Although colorectal cancer screening programs have been introduced in select provinces, to date a national colorectal cancer screening program has not been implemented in Canada. Consequently, health education and patient vigilance regarding risk awareness and preventive screening are encouraged. The ability to understand cancer information is an essential health care skill and allows individuals to engage in meaningful conversation with providers to assess their risk of disease and agree on best practices appropriate to the determined risk.[23,24] The need for shared decision making is most compelling in cancer care where numerous treatment options exist, and where different benefits and risks must be evaluated under conditions of uncertainty.[25] As a component of decision making, risk comprehension involves the ability to judge the severity of potential harm which, in turn, depends on understanding the health message and numeric risk estimates.[26]

Other factors which likely affect numeracy skill are participants' levels of math anxiety[27] and the level of attained education. Risk comprehension skill is also influenced by prior experience and familiarity of information.[8,28-30] Risk comprehension

Author References

1 Faculty of Health Sciences University of Western Ontario London, ON
2 Department of Health Studies and Gerontology Faculty of Applied Health Sciences University of Waterloo, Waterloo, ON
Correspondence: Laurie Hoffman-Goetz Department of Health Studies and Gerontology, Faculty of Applied Health Sciences, University of Waterloo, 200 University Avenue West, Waterloo, ON N2L 3G1, Fax: 519-746-2510, Email: lhgoetz@healthy.uwaterloo.ca

proficiency may reflect a familiarity with terms and concepts associated with risk that constitute specialized content vocabulary.[31,32] Assorted health care experiences can also provide context from which the individual can draw upon in order to enhance comprehension of the intended health care message.

With Canadians increasingly using the Internet as an access point to health care information,[22] the purpose of this study was to determine the influence of prose literacy skill, general- and health-context numeracy skill, math anxiety, level of attained education and familiarity of subject matter on older adults' ability to understand Internet-based cancer risk information.

Methods

Participants and procedures

A convenience sample of 140 older adults was recruited from Southern Ontario communities. For study inclusion, participants were required to: (1) be 50 to 90 years of age, (2) reside independently within the community, and (3) read and comprehend English. Individuals volunteered for participation with the awareness that they would be required to read English-language information pertaining to health issues. Participants were excluded if they had been diagnosed with any type of cancer. Request for participation was publicized at regional public libraries, community seniors' centres and through advertisements in local newspapers. Eligible participants were asked to commit to one face-to-face interview session with an estimated participant burden of 60 to 90 minutes. Public transportation was available at each interview site and each location was wheelchair accessible. The first part of the interview involved collecting demographic details from the participants, as well as scores on functional health literacy,[33] general-context numeracy,[10] health-context numeracy[9] and math anxiety.[34] The second part of the interview assessed participants' comprehension of online colorectal cancer information. Participants were offered a $40.00 stipend as reimbursement for miscellaneous costs.

Functional health literacy was assessed using the Short Test of Functional Health Literacy for Adults (STOFHLA).[33] This assessment consists of 36 prose multiple-choice questions and 4 numeracy questions. Correct responses on each of the prose and numeracy questions are assigned 2 and 7 points respectively, with a maximum score of 72 for the prose subscale and a maximum score of 28 for the numeracy subscale. A score from 0 to 55 indicates inadequate functional health literacy reflective of individuals who often misread very simple materials. Scores between 56 to 66 indicate marginal health literacy and scores between 67 to 100 indicate adequate skill.[33] The STOFHLA has good internal consistency, reliability (Cronbach's α = 0.98) and validity compared with TOFHLA (r_s = 0.91) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (r_s = 0.80).[33]

General context numeracy was assessed using a three-question general context numeracy assessment. This instrument assesses the individual's concept of probability and ability to convert percentage to proportion, and vice versa.[10,12] Scores range from 0 to 3. This instrument has adequate internal consistency.[9] Scores from this numeracy index are consistent with assessed National Adult Literacy Survey (NALS) quantitative literacy scores.[35]

Health context numeracy was assessed using an eight-item assessment.[9] The scale measures participants' ability to discern differences in magnitude of health risks and perform mathematical operations using percentages and proportions contextualized to health.[9] Participants score 1 point for each correct response with scores ranging from 0 to 8. Internal consistency was reasonable (Chronbach's α = 0.74, 0.70 and 0.75).[9]

Finally, math anxiety was assessed using the Abbreviated Math Anxiety Scale (AMAS), a nine-item scale with strong internal consistency (Cronbach's α = .90) and test-retest reliability (r = .85).[36] Test item scores range from 1 (low anxiety) to 5 (high anxiety) with a maximum test score of 45. The test requires participants to indicate their anxiety level in mathematics-based situations.[36]

The latter part of the interview was devoted to the assessment of risk comprehension. Participants read two separate Internet articles of consumer-oriented, colorectal cancer prevention information from the Canadian Cancer Society (CCS) Web site. The Internet articles were selected for similarities in terms of the cancer type, font size and readability. Internet article selection was based on the following criteria: (1) ≥ 6 numerical references, (2) numerical references in number or text form, (3) a maximum grade 12 reading level (determined by SMOG readability assessment),[37] and (4) a maximum length of 3 pages.

Eligible Internet articles were screened by the researchers and community cancer prevention partner organizations for information judged to be "common" or "uncommon", and one article was selected to represent each of these categories. Common information included material that was widely publicized, easily accessible, and that replicated general CCS introductory information available for all cancer types. For online seekers, this single page was one of the first links within a list of colorectal cancer topics and had a grade 10 SMOG readability score.

The second Internet article focused on a less common aspect of colorectal cancer: genetics. This information, 1.25 pages in length, scored a grade 11-12 SMOG rating. Despite an increased awareness of hereditary influences on disease, public understanding of genetics is often limited.[38-40] Consequently, the CCS colorectal cancer and genetics Internet article was chosen to represent information considered uncommon to the general public. Community cancer prevention education partners contributed to Internet article selection.

Internet article information was printed on 8½ by 11 inch paper with 14-type font. Printed versions were used to control for the potential confound of computer skill diversity. Given the reality of Internet site updating, the printed pages ensured consistency of information over the course of the investigation.

Multiple-choice prose and numeracy questions, based on the Internet article content were used to evaluate participant comprehension of the risk information. Prose and numeracy comprehension questions were

written at grade 8 to 9 readability. The comprehension questions were designed to capture participant understanding of the intended cancer message using health literacy (e.g. "What does incidence mean?") as well as their understanding of health numeracy (e.g. "What percentage of men died from colorectal cancer?"). The research team reviewed the comprehension test questions (contributing to face validity and content validity) and the questions were piloted with 30 older adults using their feedback for instrument revision. Participants were allowed unrestricted use of the printed Internet articles to respond to the comprehension questions. Simultaneous presentation of the two Internet articles allowed the participant to select which page to begin with.

Statistical analysis

All analyses were conducted with SPSS, Version 14.0 (SPSS, 2005). Descriptive statistics and participant scores for functional health literacy (STOFHLA), numeracy and math anxiety were summarized. Using multiple regression analysis, the authors considered the following as response variables: (1) total risk comprehension scores (2) risk comprehension scores from the common Internet article and (3) risk comprehension scores from the uncommon Internet article. Chosen *a priori*, explanatory variables included functional health literacy (STOFHLA), general context numeracy, health context numeracy, math anxiety and level of attained education. The explanatory variables of age, self-rated English skill, reading frequency, self-rated statistical understanding and income were included in subsequent regression modelling. Gender was kept in all regression equations regardless of statistical significance.

The non-parametric Wilcoxon Signed Ranks test was used to determine differences between common and uncommon Internet article test scores. The Mann-Whitney U test determined score differences between genders. In all analyses, a p value of 0.05 was taken to indicate a difference that was unlikely to arise from chance alone.

Results

Demographic characteristics of participants

Participants ranged in age from 50 to 90 years with 65% of participants ranging from 50 to 69 years. There were more women (n = 103, 73.6%) than men (n = 37, 26.4%) and the majority of participants was retired (63.6%), well-educated (52.9% college or university degree) and at a lower annual income level (< $35,000; 56.5%). Most participants (n = 102, 72.9%) owned a computer and had access to the Internet. Further characteristics of this convenience sample are described elsewhere.[4]

Literacy and numeracy profiles

Table 1 gives the range of health literacy prose skill, numeracy skill and math anxiety scores. There were no significant differences between men and women on total STOFHLA scores (Mann-Whitney = 1797.5, p = 0.52), on the STOFHLA prose score (Mann-Whitney = 1878.5, p = 0.89), or the STOFHLA numeracy score (Mann-Whitney = 1819.5, p = 0.57). Men ($\bar{x}$ = 20.02, 95% CI = 17.71, 22.35) had less math anxiety than women ($\bar{x}$ = 25.09, 95% CI = 23.41, 26.77) (Mann-Whitney = 1136.50, p = 0.001).

Participant subjective risk appraisal

Participants were asked to respond to questions assessing their subjective appraisal of risk. Almost 59% of participants suggested that a 1 in 16 lifetime probability of developing colorectal cancer constituted a high-risk situation (response range = low, medium, high). More than three quarters of participants (76%) indicated that they would seek screening for colorectal cancer knowing that their lifetime risk for developing colorectal cancer was 1 in 14 for men and 1 in 16 for women.

Thirty percent of participants were unable to correctly list examples of first degree family members. Participants with adequate functional health literacy were better able to correctly respond to this task than those in the lower functional health literacy categories (χ^2 = 10.02, df = 2, p = 0.004).

TABLE 1
Prose literacy, numeracy and math anxiety assessment scores

Variable	Total Mean Scores (95% Confidence Interval)
STOFHLA prose	63.5/72 (61.54, 65.45)
STOFHLA numeracy	26.20/28 (25.58, 26.81)
Health numeracy	5.9/8 (5.54, 6.20)
Math anxiety	23.8/45 (22.37, 25.21)
STOFHLA total	89.7/100 (87.47, 91.93)

Variable	Total %
STOFHLA level	Inadequate = 2 Marginal = 7 Adequate = 91
General numeracy	0-1 correct = 55 2 correct = 29 3 correct = 16

Risk comprehension

The mean response score for total risk comprehension (combined common and uncommon Internet articles) was 16.8/22 (95% CI = 16.19, 17.38). There was no significant gender difference in risk comprehension test scores. There was a significant difference between participant scores on the common and uncommon colorectal cancer Internet articles (Wilcoxon Signed Ranks = -7.248, p < 0.01). Individuals scored better on the common Internet-based information (mean = 9.14, 95% CI = 8.85, 9.44) than the uncommon information (mean = 7.64, 95% CI = 7.25, 8.03).

Regression modelling of risk comprehension

To assess the contributions of STOFHLA health literacy skill, general context numeracy skill, health context numeracy skill, math anxiety and attained education (*a priori*

explanatory variable set) on total risk comprehension scores, a multiple regression analysis was performed (see Table 2). Controlling for gender, approximately 60% of the variation in participant risk comprehension (total scores) was accounted for by the *a priori* explanatory variable set of: STOFHLA prose skill, STOFHLA numeracy skill, general context numeracy skill, health context numeracy skill, math anxiety and attained education ($F = 27.21$, $df = 7$, $p < 0.01$, $R^2 = 0.598$). Further modelling that incorporated the explanatory variables of income, self-rated English language skill, reading frequency and self-rated statistical understanding did not contribute to the final model. The final, most parsimonious regression model included STOFHLA prose skill, STOFHLA numeracy skill, health context numeracy skill and participant age, and accounted for 57% of the variance in participant risk comprehension total scores ($F = 35.244$, $df = 5$, $p < 0.01$, $R^2 = 0.568$).

Additional regression modelling used the common and uncommon risk comprehension scores separately as response variables. Controlling for gender, 38% of the variation in risk comprehension of the common Internet-based information was accounted for by the *a priori* explanatory variable set ($F = 11.08$, $df = 7$, $p < 0.01$, $R^2 = 0.377$). Further modelling revealed that STOFHLA numeracy, health context numeracy and participant age produced the most parsimonious regression model ($F = 18.486$, $df = 4$, $p < 0.01$, $R^2 = 0.354$). No other explanatory variables significantly contributed to the regression model.

The *a priori* explanatory variable set accounted for 56% of the variation in risk comprehension of uncommon Internet-based colorectal cancer information ($F = 23.453$, $df = 7$, $p < 0.01$, $R^2 = 0.562$). The most parsimonious model included STOFHLA prose skill, general-context numeracy skill, health-context numeracy skill and controlled for gender ($F = 34.675$, $df = 4$, $p < 0.01$, $R^2 = 0.507$). No other explanatory variables significantly contributed to the regression model.

Almost 60% of the variability in total and uncommon comprehension scores of cancer risk information was explained by prose and numeracy skill. Only 35% of the variation in risk comprehension of common colorectal cancer information can be attributed to numeracy skill (prose skill was not a significant predictor).

TABLE 2
Multiple regression modelling of participant comprehension of Internet-based colorectal cancer information

Explanatory Variable	Common Internet Information	Uncommon Internet Information	Combined Common and Uncommon Information
	β (95% CI)	β (95% CI)	β (95% CI)
Gender	0.118 (-0.44, 0.67)	0.30 (-0.36, 0.96)	0.00 (-0.92, 0.92)
Age	-0.26 (-0.53, -0.006)*	-0.32 (-0.65, 0.009)	-0.678 (-1.14, -0.21)*
STOFHLA prose	0.014 (-0.01, 0.04)	0.07, (0.04, 0.09)**	0.067 (0.03, 0.11)**
STOFHLA numeracy	0.087 (0.02, 0.16)**	0.043 (-0.04, 0.13)	0.10 (-0.017, 0.218)
General numeracy	-0.13 (-0.39, 0.14)	0.58 (0.28, 0.89)**	0.466 (-0.002, 0.89)
Health numeracy	0.401 (0.26, 0.54)**	0.38 (0.20, 0.56)**	0.838 (0.60, 1.07)**
Math anxiety	-0.004 (-0.35, 0.028)	-0.006 (-0.4, 0.031)	-0.01 (-0.06, 0.04)
Education	0.15 (–0.12, 0.43)	0.21 (-0.11, 0.53)	0.363 (-0.09, 0.82)

Overall Model	F	df	R2
± Total combined	27.21	7	0.598 **
‡[1] Final total combined	35.24	5	0.568 **
± Common	11.08	7	0.377 **
‡[2] Final common	18.49	4	0.354 **
± Uncommon	23.45	7	0.562 **
‡[3] Final uncommon	34.675	4	0.507 **

Note:

β = Beta coefficient, CI = Confidence interval

* Significant at $p < 0.05$

** Significant at $p < 0.01$

± Model Variables: STOFHLA prose, STOFHLA numeracy, general numeracy, health numeracy, math anxiety and attained education

‡[1] Parsimonious Final Model = STOFHLA prose and numeracy, health numeracy, age

‡[2] Parsimonious Final Model = STOFHLA numeracy, health numeracy, age

‡[3] Parsimonious Final Model = STOFHLA prose, general numeracy, health numeracy (gender controlled in all models)

Discussion

While recognizing the influence of patient characteristics (i.e., social support, health status)[20,42] and presentation format (i.e., gain/loss framing, graphical vs. text)[11,43,44] on risk comprehension ability, this study focused on the influence of prose and numeracy skill, math anxiety, level of attained education and information context on the ability of older Canadians to understand Internet-based colorectal cancer prevention information. While the authors found that there was adequate risk comprehension skill among older adults participating in this study, and that comprehension of common cancer-prevention information was better than comprehension of uncommon cancer-prevention information, the main findings of the study were regarding the role of health-context numeracy skill.

To our knowledge, no other published work has included risk comprehension of online cancer-prevention information using the health-context numeracy instrument. Poor general-context numeracy skill has been linked to decreased accuracy in assessing and personalizing cancer risk.[10,11,18,20] Although health-context numeracy skill predicted comprehension success of both common and uncommon online colorectal cancer pages, basic (STOFHLA) numeracy ability predicted participants' comprehension of common online prevention information only. In contrast, general-context numeracy skill predicted comprehension of the more challenging or uncommon information but not comprehension of the common colorectal cancer risk information.

To demonstrate comprehension of common Internet article information, participants were required to spot, for example, the value that signifies "the risk of death from colorectal cancer for men" (i.e., 1 in 14). The STOFHLA numeracy instrument seems to be best aligned with the most basic numeracy skill category of number identification.[41] Yet participants responding to common Internet article comprehension questions also required greater numeric proficiency than that required by STOFHLA (e.g. to calculate the percentage of men dying from colorectal cancer) – a skill level characteristic of the advanced categories in the health numeracy framework.[10,41] Although the uncommon Internet article information also challenged participants' basic and advanced numeracy skill, STOFHLA numeracy skill was not a significant predictor. Given the lack of general public knowledge regarding genetic influences on colorectal cancer,[45,46] it is possible that the basic numeracy skill was not enough, due to a lack of knowledge content regarding the genetic basis of disease.[30] Established evidence has demonstrated that breadth of vocabulary and domain knowledge increased comprehension of information.[46] Topic familiarity also enhances individual ability to understand risk-based information.[8,44,47,48] It is not surprising that prose health literacy skill contributed only to comprehension of uncommon colorectal cancer information. The terms and phrases used within the genetic information may have required a vocabulary distinct from that needed to understand the common Internet article. Consequently, those producing health promotion messages may wish to repeat less familiar terms and include examples of key concepts.[44] The interactive capabilities attributable to online health sources present an excellent avenue for unobtrusively incorporating such information props.

Not unexpectedly, older age predicted poorer comprehension scores for the combined common/uncommon risk assessment and for the common assessment but not for uncommon risk comprehension assessment scores. A recent evaluation of older adults' comprehension of Internet-based colorectal cancer information also revealed limited understanding of the intended message.[49] The relationship between increased age and lower literacy and numeracy skill has been previously established.[12,15,33] Current findings are consistent with international analyses of adult literacy and numeracy skill. In fact, an inverse relationship between age and literacy skill exists even after controlling for educational attainment.[50] The International Adult Literacy Survey (IALS) reports educational attainment as an unreliable predictor of literacy skill.[51] The authors also found that level of formal education was not a significant predictor of literacy skill in the current study. While education plays a key role in the development of individual prose and numeracy skill, evidence suggests that the relationship between education and literacy skill involves other factors (i.e., continued education, occupational experience, motivation, cognitive changes) that contribute to literacy skill acquisition, preservation and loss over the course of a lifetime.[51] In fact, educational attainment as a proxy estimate of adult literacy skill can result in considerable error.[51]

Approximately 76% of participants indicated that they would seek screening for colorectal cancer based on an awareness of their lifetime risk. However, recent statistics show that screening for colorectal cancer among Canadian adults 50 years and older is less than 15%.[21] While recognizing the inconsistency between actual screening for colorectal cancer and the intention to be screened, the number of older adults indicating their intention to have preventive screening after reading information on colorectal cancer risk was promising. Alternatively, it was a matter of concern that 30% of participants were unable to identify examples of first degree family members from those listed in the cancer and genetics information, and that this was linked to inadequate functional health literacy skill. Indeed, this finding takes on greater importance given current screening recommendations for all first-degree family members of individuals with known genetic markers for colorectal cancer.[21]

In addition, personal connection to information enhances thinking about the content and promotes understanding through increased attention to the information.[48] Study participants had no apparent personal threat of colorectal cancer and, therefore, may have been less inclined to attend to educational colorectal cancer messages.

Limitations

There are limitations to this study. The risk comprehension skill of seniors living independently in the community may be different from those who are ill. Illness can affect an individual's cognitive reasoning and decision-making skills, altering the ability to accurately comprehend risk information.[52] Similarly, the literacy skill of participants is not representative of younger

Canadians. However, the higher propensity for cancer illness among older adults guided our study design. Therefore, the current findings reflect a well-, rather than a health-compromised, group of seniors.

Selection bias is possible given that literate individuals are more likely to volunteer for a study on comprehension of health information. Individuals who did not visit the libraries or seniors' centres would have limited representation within the study. The use of a convenience sample drawn from these locations may have discouraged older adults who lacked transportation (e.g., those who cannot drive, were physically disabled). However, there was diverse representation of socio-economic status of participants, providing a cross sectional account of seniors. Hence, this convenience sample reflected a group of relatively mobile, active, older adults.

An additional limitation is the lack of psychometric validation of the properties of the general- and health-context numeracy indexes, despite widespread use by researchers in the field.[9,10,53-55] Preliminary investigations reveal adequate reliability[9] for both the general- and health-context numeracy instruments. Health numeracy is best described as "a work in progress".[10] As a result, the three numeracy measures used in this study represented those instruments that were available at the time of study conception and were used to ensure comprehensive assessment of participants' numeracy skill.

Patient characteristics[42] as well as presentation format[31,43,44] influence risk comprehension ability. The authors purposefully limited their investigation of cancer risk comprehension to the areas of health literacy and health numeracy. The selection of explanatory variables was a planned response to address the gaps in the research literature on health numeracy as it relates to risk comprehension skill.

Lastly, the reading levels of the online health information scored at grade 10 and 11/12. These reading grade levels were higher than the grade 5/6 readability level recommended for the general public.[56] This is an important limitation in the consideration of information comprehension. Yet, participants examined the same information they would have reviewed though naturalistic and independent searching of the CCS Web site.

Conclusion and implications for practice

This research is the first to investigate the influence of health literacy skill, particularly numeracy skill, on the ability of older Canadians to comprehend online colorectal cancer-prevention information. The findings revealed that health-context numeracy skill was a consistent predictor of participant ability to comprehend risk within common as well as more challenging cancer prevention information.

Finding that participant risk comprehension was jointly facilitated by prose and numeracy skill highlights the need for clarification of terms and concepts within educational online health information. Thus, impersonal prevention messages may be enhanced by repetition of terms and detailed explanation of less familiar concepts to aid reader comprehension of the colorectal cancer-prevention information. The fact that even basic numeracy tasks may be perceived as more demanding if positioned within an unfamiliar context challenges information specialists and Web designers to construct Internet-based information to accommodate diverse health literacy skills.

There is the increasing expectation that individuals take an active role in the decisions about their health care. Continued investigation is needed to refine the concept of health numeracy, develop comprehensive numeracy assessment instruments, and further investigate the relationship between health prose and numeracy skill with all age cohorts, pertaining to various chronic illnesses, and among diverse ethnic groups.

Acknowledgements

Research supported by a grant from the Canadian Institutes of Health Research. The authors thank our community partner, the Cancer Prevention and Early Detection Network of Waterloo Region, E. Harvey for advice regarding statistical analyses, and the 140 individuals who participated in the study.

References

1. Nielsen-Bohlman L, Panzer A, Kindig DA, eds. Institute of Medicine (IOM). Health literacy: A prescription to end confusion. Washington, DC: The National Academies Press, 2004.

2. Public Health Agency of Canada (PHAC). What determines health? URL: http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php .

3. Baker DW, Gazmararian JA, Sudano J, Patterson M. The association between age and health literacy among elderly persons. J Gerontol B Psychol Sci Soc Sci. 2000;55:S368-S374.

4. Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, et al. Health literacy and use of outpatient physician services by Medicare managed care enrollees. J Gen Intern Med. 2004;19:215-220.

5. Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. J Gen Intern Med. 1998;13:791-798.

6. Fuller R, Dudley N, Blacktop J. Risk communication and older people-understanding of probability and risk information by medical inpatients aged 75 years and older. Age Ageing. 2001;30:473-476.

7. Gazmararian JA, Baker DW, Williams MV, Parker RM, Scott TL, Green DC, et al. Health Literacy among medicare enrollees in a managed care organization. JAMA. 1999;281:545-551.

8. Health Canada. How does literacy affect the health of Canadians? Ottawa: Health Canada. 2003. URL: http://www.travelhealth.gc.ca/ph-sp/literacy-alphabetisme/literacy-eng.php.

9. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. Med Decis Making. 2001;21:37-44.

10. Schwartz L, Woloshin S, Black W, Welch H. The role of numeracy in understanding the benefit of screening mammography. Ann Intern Med. 1997;127: 966-972.

11. Schwartz SR, McDowell J, Yueh B. Numeracy and the shortcomings of utility assessment in head and neck cancer patients. Head Neck. 2004;26:401-407.

12. Sheridan S, Pignone M, Lewis C. A randomized comparison of patients' understanding of number needed to treat and other common risk reduction formats. J Gen Intern Med. 2003;18:884-892.

13. Williams MV, Parker RM, Baker DW, Parikh NS, Pitkin K, Coates WC, et al. Inadequate functional health literacy among patients at two public hospitals. JAMA. 1995;274: 1677-1682.

14. Wolf MS, Gazmararian JA, Baker DW. Health literacy and functional health status among older adults. Arch Intern Med. 2006;165:1946-1952.

15. Nurss J, Parker RM, Baker DW. TOFHLA: Test of Functional Health Literacy for Adults. Peppercorn Books and Press Inc. 1995.

16. Golbeck AL, Ahlers-Schmidt CR, Paschal AM, Dismuke SE. A definition and operational framework for health numeracy. Am J Prev Med. 2005;29:375-376.

17. Davids SL, Schapira M, McAuliffe TL, Nattinger AB. Predictors of pessimistic breast cancer risk perceptions in a primary care population. J Gen Intern Med. 2004; 19:310-315.

18. Sheridan SL, Pignone M. Numeracy and the medical student's ability to interpret data. Eff Clin Pract. 2002;5:35-40.

19. Woloshin S, Schwartz LM, Moncur M, Gabriel S, Tosteson AN. Assessing values for health: numeracy matters. Med Decis Making. 2001;21:382-390.

20. Weinstein ND, Atwood KA, Puleo E, Fletcher R, Colditz GA,Emmons K. Colon cancer: Risk perceptions and risk communication. J Health Commun. 2004;9: 53-65.

21. Canadian Cancer Society. Canadian Cancer Society Statistics, 2006. URL: http://www.cancer.ca.

22. Statistics Canada. Households using the Internet from home, by purpose of use. Government of Canada, 2004. URL: http://www40.statcan.ca/l01/cst01/arts52b.htm.

23. Eysenbach G. Towards the millennium of cybermedicine. J Med Internet Res. 1999:1;S1,e2.

24. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes least two to tango). Soc Sci Med. 1997;44:681-692.

25. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? BMJ. 1999;319:780-782.

26. Weinstein ND. What Does It Mean to Understand a Risk? Evaluating risk comprehension. J Natl Cancer Inst Monogr. 1999; 25:15-20.

27. Ashcraft MH, Kirk EP. The relationship between working memory, math anxiety, and performance. J Exp Psychol Learn Mem Cogn. 2001;27:157-175.

28. Speros C. Health Literacy: concept analysis. J Adv Nurs. 2004;50:633-640.

29. Wilson-Fisher J. The crucial link between literacy and health. Ann Intern Med. 2003;139:875-878.

30. Riche JM, Reid JC, Robinson RD, Kardash CM. Text and reader characteristics affecting the readability of patient literature. Read Improvement. 1991;28:287-292.

31. Kreuter MW. Dealing With competing and conflicting risks in cancer communication. J Natl Cancer Inst Monogr. 1999;25:27-35.

32. Jones CJ. CBA's that work. Assessing student's math content-reading levels. Teach Exceptional Child. 2001;34:24-28.

33. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. Patient Educ Couns. 1999;38:33-42.

34. Hopko DR, Mahadevan R, Bare RL, Hunt MK. The Abbreviated Math Anxiety Scale (AMAS): Construction, validity, and reliability. Assessment. 2003;10:178-182.

35. Schwartz LM, Woloshin S, Welch HG. Can patients interpret health information? An assessment of the medical data interpretation test. Med Dec Making. 2005;25:290-300.

36. Hopko DR. Confirmatory factor analysis of the Math Anxiety Rating Scale-Revised. Educ Psychol Meas. 2003;63:336-351.

37. McLaughlin GH. SMOG grading – a new readability formula. J Read. 1969;12: 639-649.

38. Boyd JH, Watkins AR, Price CL, Fleming F, DeBaun MR. Inadequate community knowledge about sickle cell disease among African-American women. J Natl Med Assoc. 2005;9:62-67.

39. Richards M. Lay and professional knowledge of genetics and inheritance. Public Underst Sci. 1996;5;217-230.

40. Lanine AD, Jayaratne TE, Sheldon JP, Kardia SLR, Anderson ES, Feldbaum M, et al. Exploring the public understanding of basic genetic concepts. J Genet Couns. 2004;13:305-320.

41. Donelle L, Arocha JF, Hoffman-Goetz L. Assessing health numeracy among community dwelling older adults. J Health Commun. 2007;12: 651-665.

42. Peters E, McCaul KD, Stefanek M, Nelson W. A heuristics approach to understanding cancer risk perception: contributions from judgment and decision-making research. Ann Behav Med. 2006;31:45-52.

43. Schapira MM, Nattinger AB, McHorney CA. Frequency or probability? A qualitative study of risk communication formats used in health care. Med Dec Making. 2001; 21:459-467.

44. Reid JC, Kardash CM, Robinson RD. Comprehension in patient literature: the importance of text and reader characteristics. Health Commun. 1994;6:327-335.

45. Ahlers-Schmidt CR, Golbeck AL, Paschal AM, Zackula R, Taylor NT. Breast cancer counts: numeracy in breast cancer information on the web. J Cancer Educ. 2006;21: 95-98.

46. Hirsch ED. Reading comprehension requires knowledge of the words and the world. 2003. URL: http://www.aft.org/pubs-reports/american_educator/spring2003/AE_SPRNG.pdf.

47. Beier ME, Ackerman PL. Age, ability, and the role of prior knowledge on the acquisition of new domain knowledge: promising results in a real-world learning environment. Psychol Aging. 2005;20:341-355.

48. Spires HA, Donley J. Prior knowledge activation: inducing engagement with informal texts. J Educ Psychol. 1998;90:249-260.

49. Friedman, DB, Hoffman-Goetz L. An exploratory study of older adults' comprehension of printed cancer information: Is readability a key factor? J Health Commun. 2007;12:423-437.

50. Statistics Canada. Learning a living: the first results of the adult literacy and life skills survey. Ottawa and Paris: Organization for Economic Co-operation and Development, 2005. URL: http://www.statcan.ca/english/freepub/89-603-XIE/89-603-XIE2005001.htm .

51. Statistics Canada. Building on our Competencies: Canadian Results of the International Adult Literacy and Skills Survey. Ottawa: Human Resources and Skills Development Canada, 2005. Catalogue no. 89-617-XIE.

52. Cassell EJ, Leon AC, Daufman SG. Preliminary evidence of impaired thinking in sick patients. Ann Intern Med. 2001; 134:1120-1123.

53. Woloshin, S, Schwartz LM, Black WC, Welch HG. Women's perceptions of breast cancer risk: how you ask matters. Med Dec Making. 1999;19: 221-229.

54. Schapira M.M, Davids SL, McAuliffe TL, Nattinger AB. Agreement between scales in the measurement of breast cancer risk perceptions. Risk Anal. 2004;24: 665-673.

55. Estrada C, Martin-Hryniewicz M, Barnes-Higgs V, Collins C, Byrd JC. Anticoagulant patient information material is written at high readability levels. Stroke. 2000; 31:2966-2970.

56. Estey A, Musseau A, Keehn L. Comprehension levels of patients reading health information. Patient Educ Couns. 1991;18: 165-169.

Colorectal cancer screening in Canada: results of a national survey

MJ Sewitch, PhD (1); C Fournier, MSc (2); A Ciampi, PhD (3); A Dyachenko, MSc (4)

Abstract

Canadian guidelines recommend colorectal-cancer (CRC) screening for individuals aged 50 to 74 years. The study objective was to estimate rates of CRC screening according to individual and geographical characteristics, and of adherence to current CRC screening guidelines. Respondents to the 2003 Canadian Community Health Survey Cycle 2.1 (aged ≥ 50 years, without past or present CRC) participated. Fecal occult blood test (FOBT) and endoscopy utilization and screening rates were calculated. The sample included 16 747 residents of Newfoundland, Ontario, Saskatchewan and British Columbia. Overall, the FOBT screening rate was 7.7% in the past year, and the endoscopy screening rate was 8.8% in the past 5 years. FOBT screening rates were higher in older and male respondents; endoscopy screening rates were higher in older respondents. Individuals aged 50 to 59 and over 90 years were least likely to have been screened. Approximately 70% of respondents were non-adherent to current CRC screening guidelines. Non-adherence rates were higher in most health regions of British Columbia. National survey data suggest CRC screening in Canada is low; younger persons and residents of British Columbia were least likely to report CRC screening.

Key words: *colorectal cancer, screening, survey, FOBT, endoscopy*

Introduction

In Canada, colorectal cancer (CRC) is the fourth most commonly diagnosed cancer and the second and third leading cause of cancer deaths in men and women, respectively.[1] CRC screening reduces both CRC incidence through removal of premalignant polyps and CRC deaths through early detection and treatment. Since 1996, several organizations have published CRC screening guidelines for average-risk individuals, defined as those 50 years of age and older with average risk for the development of CRC. Canadian guidelines recommend fecal occult blood testing (FOBT) every 1 to 2 years[2-4] whereas the US guidelines recommend annual FOBT.[5,6] For other screening modalities, similar periodicities are advocated by Canada and the US: every 10 years for colonoscopy and every 5 years for each of flexible sigmoidoscopy and double contrast barium enema, although the US guidelines also recommend a combination of annual FOBT with flexible sigmoidoscopy every 5 years.

Despite the widespread distribution of CRC screening guidelines, CRC screening is underutilized. In the US, several studies have employed national survey data and collected information through the use of either random-digit-dialing or in-person interviews. Research based on data from the National Health Interview Survey,[7] the Behavioral Risk Factor Surveillance System,[8] the Community Quality Index,[9] the California Health Interview Survey[10] and the Health Information National Trends Survey[11] revealed that CRC screening rates vary from 15% to 65% depending on the time interval under study. In Ontario, research derived from either administrative or survey data estimates that less than 25% of the screen-eligible population has been screened.[12-14] In Alberta, a population-based survey revealed that only 14.3% of average-risk individuals were considered up-to-date with CRC screening.[15]

As CRC screening advances to the forefront of preventive health care through public and professional awareness, rates of CRC screening in Canada are of growing interest. However, the extent to which Canadians are screened for CRC according to guidelines remains unclear. Moreover, little is known about the characteristics of the individuals who undergo CRC screening and the use of CRC screening procedures over time. With the launching of several provincial CRC screening programs in Canada, understanding CRC screening disparities is pivotal to fostering effective planning, implementation and functioning of CRC screening endeavors. Thus, the purpose of this population-based study was to estimate rates of 1) FOBT and endoscopy as CRC screening procedures; and 2) adherence to current CRC screening guidelines.

Methods

Data sources

The main data source was the Statistics Canada Canadian Community Health Survey (CCHS) Cycle 2.1 (January to December 2003),[16] which aimed to provide estimates of health determinants, health status and health system utilization in Canada. This survey included household residents aged 12 years and older in all provinces and territories. Residents living

Author References

1 Department of Medicine, McGill University, Montreal, QC
2 Division of Clinical Epidemiology, Research Institute of the McGill University Health Centre, Montreal, QC
3 Department of Epidemiology and Biostatistics, McGill University, Montreal, QC
4 Department of Epidemiology and Community Studies, St. Mary's Hospital Center, Montreal, QC
Correspondence: Maida J. Sewitch, PhD, 687 Pine Avenue West, V Building, The Royal Victoria Hospital, Montreal QC H3A 1A1, Tel.: 514-934-1934 local 44736, Fax.: 514-934-8293, Email: maida.sewitch@mcgill.ca

on Indian Reserves or in remote areas, and full-time members of the Canadian Armed Forces were excluded. The CCHS Cycle 2.1 survey contained basic socio-demographic information on all respondents in all health regions. However, the CRC screening module was administered at the discretion of health regions. Respondents to the CRC screening module were from all health regions of Newfoundland and British Columbia, and from 14 of 37 and 7 of 11 health regions of Ontario and Saskatchewan, respectively.[17] *Health regions* are defined by provincial health ministries and generally comprise legislated administrative areas representing geographic areas of responsibility for hospital boards or regional health authorities.[18] Survey data are non-nominative; respondents were not identified.

Study population

The study population included survey respondents who completed the CRC screening module and reported being 50 years of age and older and without past or present CRC. Respondents failing to provide information on when both FOBT and endoscopy were last performed were excluded. Socio-demographic characteristics included age, sex, highest level of education achieved and household income. Clinical characteristics included bowel disease (having received a diagnosis of either Crohn's disease or ulcerative colitis from a health care professional). Geographical characteristics included residential area (urban vs. rural), health region and province of residence.

Outcome variables

FOBT and endoscopy (defined as sigmoidoscopy or colonoscopy) screening and utilization rates were based on questionnaire responses that assessed when the procedure was last performed and the indication for the procedure (screening, non-screening). *Screening rates* were derived from screening procedures, which were defined as those performed for "regular check-up", "age", "race", or "family history of CRC". The degree of an affected family member was not assessed. *Utilization rates* were derived from screening and non-screening procedures, which were defined as those performed for "follow-up of previous problem" or "other reason". FOBT can be used in a non-screening context, for example, to detect the presence of blood in the stool of a patient with anemia. Three adherence rates were defined according to CRC screening guideline-recommended periodicities in place at the time of the study. (1) Adherence to FOBT screening guidelines was defined as having an FOBT in the past 2 years; (2) Adherence to endoscopy screening guidelines was defined as having an endoscopy in the past 10 years; (3) Adherence to current CRC screening guidelines was defined as either (1) or (2). The three adherence rates, which were based on procedures performed for *all* indications, provide an estimate of the number of respondents considered up-to-date with CRC screening. The underlying assumption is that once the procedure is performed, repeat testing for screening purposes should follow guideline-recommended periodicities.

Statistical analysis

Descriptive statistics were used to characterize the study population overall and according to screening modality. Screening rates were calculated as the number of respondents reporting a screening procedure, divided by the number of respondents reporting a screening procedure plus those reporting never undergoing the procedure, according to the timing of the last screening procedure. Respondents who underwent the procedure for non-screening purposes were excluded. Utilization rates were calculated as the number of respondents reporting either a screening or non-screening procedure divided by the total number of respondents in the study population, according to the timing of the last procedure. FOBT rates were calculated according to the following 5 time intervals: less than 1 year ago, 1 to 2 years ago, 2 to 3 years ago, more than 3 years ago and never. Endoscopy rates were calculated according to the following 4 time intervals: within the last 5 years, 6 to 10 years ago, more than 10 years ago and never. These time intervals differ from the guideline-recommended periodicities to allow for comparisons over time. Overall screening and utilization rates were computed for the entire study population. Screening rates were also computed by sex, age group, household income level, education level, bowel disease status and geographical areas (residential area, health region and province of residence).

Rates were computed by aggregating weighted data over the participating health regions. Rates may not be representative of the entire province when only some health regions are sampled. Thus, only *regional* screening rates were reported for Ontario and Saskatchewan. By comparison, *regional* and *provincial* screening rates were reported for Newfoundland and British Columbia, where all health regions were sampled. Rates for the 3 adherence outcomes were calculated overall and according to health regions. Although rates of adherence to current CRC screening guidelines were based on FOBT and endoscopy utilization, respondents having valid information on only one procedure were included and classified accordingly. Bootstrap weights provided by Statistics Canada were employed to compute a 95% confidence interval (95% CI) using the BOOTVARE_V30 program (Version 3.0).[19] All analyses were performed using SAS statistical software.[20]

The sizes of both the Canadian population at survey time and the study population (i.e. number of Canadians represented by the respondents) were estimated using the weighted design previously mentioned. All figures presented are weighted values, in keeping with the policies of Statistics Canada.

Results

Study population

The CRC screening module was administered to 39 178 individuals (Figure 1). Of these, 16 747 respondents met eligibility criteria and were estimated to represent 2 394 124 Canadians (according to weighting procedures). The size of the Canadian population aged 12 and over was estimated at 26 578 128. Of the eligible respondents, 16 545 and 16 648 provided information on utilization of FOBT and endoscopy, respectively; 14 482 and 13 949 provided information on FOBT and endoscopy screening, respectively.

Table 1 presents the socio-demographic, clinical and geographical characteristics of the study population overall and according to screening modality. Overall, more of the respondents were female, aged 50 to 64, post high-school graduates, born in Canada, white, not employed, without bowel disease, living in urban areas and from British Columbia. Of the 14 482 respondents with FOBT screening information, 21.6% underwent FOBT screening in their lifetimes. Compared to the total study population, a greater percentage of those reporting FOBT screening were aged 50 to 64 and were not employed outside the home. Of the 13 949 respondents with endoscopy screening information, 11.3% underwent endoscopy screening in their lifetimes. Compared to the total study population, a greater percentage of those reporting endoscopy screening were not employed outside the home and were residents of Ontario; a smaller percentage were residents of British Columbia.

FOBT screening rates

Table 2 presents FOBT screening rates by time interval, according to socio-demographic, clinical and geographical characteristics. Overall FOBT screening rates were 7.7% in the past year, 5.1% 1 to 2 years ago, 2.5% 2 to 3 years ago, and 6.3% over 3 years ago; 78.4% never had a screening FOBT. FOBT screening rates in the past year and 1 to 2 years ago were higher in males, those with bowel disease and those aged 65 years and older; rates were lowest among the 50 to 59 year age group. No rural vs. urban difference was observed. Provincial FOBT screening rates were higher in residents of British Columbia compared to Newfoundland. Health regional FOBT screening varied within each province (Table 3). Across the 43 health regions of all provinces, FOBT screening rates in the past year ranged from 2.4% to 21.5% and rates of never undergoing FOBT screening ranged from 54.3% to 89.2%. In comparison, overall FOBT utilization rates were: 9.1% in the past year, 6.0% 1 to 2 years ago, 11.8% over 3 years ago; 69.3% never had an FOBT (data not shown).

Endoscopy screening rates

Table 4 presents endoscopy screening rates by time interval, according to socio-demographic, clinical and geographical characteristics. Overall endoscopy screening rates were 8.8% in the past 5 years and 1.5% in the past 6 to 10 years; 88.7% never had a screening endoscopy. Endoscopy screening rates in the past 5 years were higher in respondents with bowel disease and those aged 65 years and older; rates were lowest among the 50 to 59 year and 90 to 100 year age groups. No rural vs. urban difference was observed. Provincial endoscopy screening rates were higher in residents of Newfoundland compared to British Columbia. Health regional endoscopy screening rates varied within each province (Table 3). Across the 43 health regions (i.e. all provinces), endoscopy screening rates in the past 5 years ranged from 4.2% to 16.5%, and rates of never undergoing endoscopy screening ranged from 81.1% to 94.3%. In comparison, overall endoscopy utilization rates were 16.7% in the past 5 years and 3.9% in the past 6 to 10 years; 75.6% never had an endoscopy (data not shown).

Adherence to FOBT screening guidelines

Table 5 shows that 15.1% of respondents were adherent to FOBT screening guidelines. Figure 2 shows that rates of adherence to FOBT screening guidelines were highest in the southern health regions of British Columbia and some health regions of Saskatchewan and Ontario. Rates of never-use of FOBT across all health regions (Figure 3) were highest in eastern health regions of British Columbia, the Saskatoon region, north-eastern Ontario and parts of Newfoundland.

FIGURE 1

Study population selection from the CCHS Cycle 2.1 CRC screening module respondents

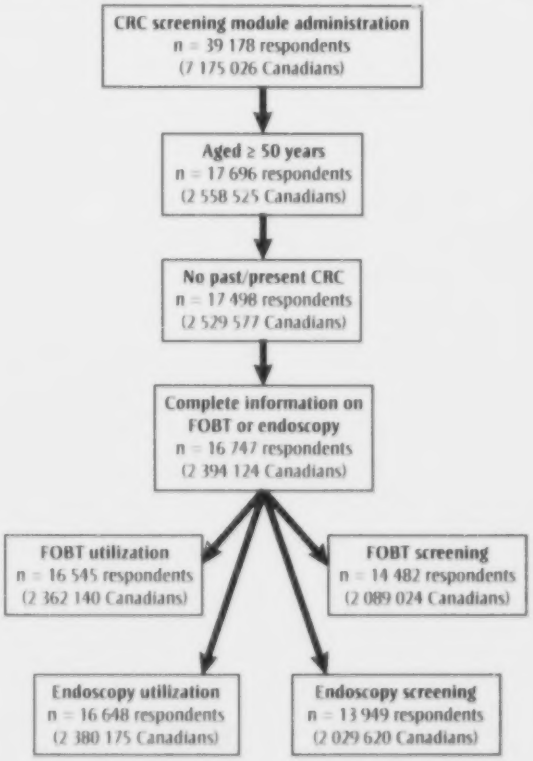

CRC screening module administration
n = 39 178 respondents
(7 175 026 Canadians)
Aged ≥ 50 years
n = 17 696 respondents
(2 558 525 Canadians)
No past/present CRC
n = 17 498 respondents
(2 529 577 Canadians)
Complete information on FOBT or endoscopy
n = 16 747 respondents
(2 394 124 Canadians)
FOBT utilization
n = 16 545 respondents
(2 362 140 Canadians)
FOBT screening
n = 14 482 respondents
(2 089 024 Canadians)
Endoscopy utilization
n = 16 648 respondents
(2 380 175 Canadians)
Endoscopy screening
n = 13 949 respondents
(2 029 620 Canadians)

TABLE 1

Socio-demographic, clinical and geographical characteristics of the study population according to FOBT and endoscopy screening status

Characteristic	Category	Overall		FOBT screening[a]		Endoscopy[b] screening	
		n (2 394 124)	%[c]	n (451 669)	%[c]	n (229 578)	%[c]
Socio-demographic							
Sex	male	1 140 566	47.6	233 372	51.7	112 541	49.0
	female	1 253 559	52.4	218 298	48.3	117 037	51.0
Age	50 to 64	1 429 679	59.7	222 473	49.3	122 450	53.3
	65+	964 446	40.3	229 197	50.7	107 128	46.7
Education	< high school	630 647	27.0	110 676	25.1	56 249	25.0
	high school grad.	462 201	19.8	89 306	20.3	42 533	18.9
	post high school	143 139	6.1	23 708	5.4	17 793	7.9
	post high school grad.	1 095 953	47.0	216 554	49.2	108 544	48.2
Country of birth	Canada	1 653 452	70.3	315 685	70.9	171 337	75.5
	other	697 280	29.7	129 554	29.1	55 543	24.5
Cultural/racial origin	white	2 067 992	88.0	405 037	91.1	205 344	90.8
	other	281 342	12.0	39 630	8.9	20 748	9.2
Household income	low to low medium	656 704	33.2	116 925	31.1	64 074	33.7
	upper medium	685 018	34.7	132 543	35.2	64 003	33.6
	high	635 229	32.1	126 742	33.7	62 152	32.7
Employment status (over past year)	full-time	864 382	37.0	126 254	28.6	68 193	30.2
	part-time	211 809	9.1	39 937	9.0	21 600	9.6
	no job	1 258 634	53.9	275 747	62.4	135 673	60.2
Clinical							
Bowel disease	yes	86 080	3.6	16 664	3.7	10 699	4.7
	no	2 305 488	96.4	434 428	96.3	218 770	95.3
Geographical							
Residential area	urban	1 895 462	79.2	355 944	78.8	183 465	79.9
	rural	498 663	20.8	95 725	21.2	46 114	20.1
Residential province	Newfoundland & Labrador	155 166	6.5	19 859	4.4	15 673	6.8
	Ontario	889 608	37.2	171 566	38.0	111 762	48.7
	Saskatchewan	168 279	7.0	31 603	7.0	15 508	6.8
	British Columbia	1 181 072	49.3	228 641	50.6	86 636	37.7

All numbers are weighted

Numbers may not be equal to the population n due to missing data

[a] Respondents reporting lifetime FOBT screening

[b] Respondents reporting lifetime endoscopy screening

[c] Based on valid responses (excludes missing values)

TABLE 2

FOBT screening rates by time interval according to socio-demographic, clinical and geographical characteristics (n[a] = 14 482)

Characteristic	Last reported FOBT screening														
	< 1 year			1 to 2 years			2 to 3 years			3+ years			never		
OVERALL	Rate	95% CI		Rate	95% CI		Rate	95% CI		Rate	95% CI		Rate	95% CI	
	7.7	7.1	8.4	5.1	4.6	5.6	2.5	2.2	2.8	6.3	5.8	6.9	78.4	77.5	79.3
Sex															
male	9.3	8.2	10.3	5.8	5.0	6.6	2.3	1.8	2.7	5.7	5.0	6.5	76.9	75.5	78.4
female	6.2	5.5	7.0	4.4	3.8	5.0	2.7	2.3	3.2	6.9	6.2	7.6	79.7	78.6	80.9
Age (years)															
50 to 64	6.6	5.7	7.4	4.5	3.8	5.1	1.8	1.5	2.2	4.8	4.1	5.4	82.4	81.2	83.6
65+	9.5	8.4	10.6	6.0	5.3	6.8	3.5	3.0	4.1	8.7	7.9	9.6	72.2	70.7	73.7
50 to 59	5.7	4.8	6.6	3.8	3.2	4.5	1.7	1.2	2.2	4.2	3.5	4.9	84.5	83.2	85.9
60 to 69	9.3	8.1	10.5	5.9	4.9	6.9	2.7	2.1	3.3	6.5	5.4	7.6	75.6	73.8	77.4
70 to 79	10.3	8.8	11.8	6.5	5.4	7.7	3.7	2.8	4.5	9.0	7.7	10.2	70.6	68.4	72.8
80 to 89	7.7	4.7	10.6	6.2	4.5	8.0	3.8	2.7	5.0	11.8	9.5	14.2	70.5	66.8	74.1
90 to 100	n/a	n/a	n/a	3.7	0.6	6.8	n/a	n/a	n/a	10.5	n/a	21.5	83.0	72.0	93.9
Residential area															
urban	7.7	6.9	8.4	4.9	4.4	5.4	2.6	2.2	3.0	6.4	5.8	7.0	78.5	77.4	79.5
rural	7.9	6.7	9.2	5.8	4.7	6.8	2.0	1.5	2.6	6.3	5.3	7.3	78.0	76.1	79.8
Education															
< high school	6.9	5.9	8.0	4.8	4.0	5.7	2.5	2.0	3.1	6.3	5.3	7.2	79.5	77.8	81.1
high school grad.	7.7	6.1	9.3	5.6	4.5	6.7	2.7	1.9	3.4	5.7	4.7	6.6	78.4	76.3	80.6
post high school	9.1	6.4	11.9	3.7	1.8	5.6	1.9	1.0	2.9	5.2	3.1	7.2	80.1	75.8	84.4
post high school graduate	8.0	7.0	9.0	5.1	4.4	5.8	2.5	2.0	3.0	6.9	6.0	7.7	77.5	76.1	79.0
Household income															
low to low medium	6.8	5.6	7.9	4.4	3.7	5.1	2.6	2.0	3.2	7.1	6.1	8.2	79.1	77.5	80.8
upper medium	7.9	6.8	9.1	4.9	4.1	5.7	2.1	1.6	2.6	7.3	6.3	8.3	77.8	76.1	79.5
high	9.0	7.5	10.5	5.7	4.7	6.8	2.8	2.0	3.5	5.0	4.0	5.9	77.6	75.4	79.7
Bowel disease															
yes	11.9	7.8	15.9	5.5	2.8	8.2	3.0	1.2	4.8	10.1	6.5	13.8	69.5	63.8	75.1
no	7.6	6.9	8.2	5.1	4.5	5.6	2.5	2.2	2.8	6.2	5.7	6.8	78.6	77.7	79.6
Residential province[c]															
Newfoundland &Labrador	3.8	2.7	4.9	2.8	1.7	3.8	2.0	0.8	3.1	6.1	4.6	7.7	85.4	83.2	87.5
British Columbia	8.1	7.0	9.2	5.1	4.3	5.9	2.1	1.7	2.5	6.4	5.6	7.3	78.4	76.8	79.9

Rate percentages represent weighted data

[a] Number of respondents providing information on FOBT screening and representing 2 089 024 Canadians

[b] Respondents categorized according to the last reported date of screening FOBT

FOBT performed for non-screening purposes are excluded

[c] Ontario and Saskatchewan provincial rates are not reported because data are not available for all health regions

n/a = not available because non-weighted data cells contained less than 5 individuals (Statistics Canada privacy protection regulation)

TABLE 3
Summary of health regional screening rates of FOBT and endoscopy by province

Province	Health regions	FOBT range[b]		Endoscopy range[b]	
	n (%)	past year	never	past 5 years	never
Overall[a]	43	2.4 to 21.5	54.3 to 89.2	4.2 to 16.5	81.1 to 94.3
Newfoundland & Labrador	6 (100%)	2.8 to 5.4	83.6 to 89.1	4.8 to 12.0	84.6 to 94.3
Ontario	14 (37.8%)	3.9 to 13.1	62.5 to 85.3	8.2 to 16.5	81.1 to 88.4
Saskachewan	7 (63.6%)	3.8 to 21.5	54.3 to 85.5	7.5 to 10.8	82.6 to 90.8
British Columbia	16 (100%)	2.4 to 15.1	56.5 to 89.2	4.2 to 13.4	83.4 to 93.8

[a] All health regions/provinces combined

[b] Range values are percentages

Adherence to endoscopy screening guidelines

A total of 20.6% of respondents were adherent to endoscopy screening guidelines (Table 5). Figure 4 shows that health regional rates of adherence to endoscopy screening guidelines were highest in southeastern British Columbia, southern Alberta, northern Ontario and parts of Newfoundland. Rates of never-use of endoscopy (Figure 5) were highest in British Columbia and parts of Newfoundland. No clear geographical pattern emerged for Saskatchewan, as less than half of provincial health regions were sampled.

Adherence to current CRC screening guidelines

In this study population, 30.1% of respondents were adherent and 69.9% were non-adherent to current CRC screening guidelines (Table 5). Figure 6 shows that non-adherence rates were highest in most health regions of British Columbia and lowest in many health regions of Ontario. Non-adherence rates for Newfoundland and Saskatchewan varied by health region.

Discussion

The overarching goal of this Canadian population-based study was to increase our knowledge of the extent to which Canadians 50 years of age and older undergo CRC screening. Our results indicate that rates of CRC screening by FOBT and endoscopy were low and subject to considerable geographic variation. Provincial screening rates (Newfoundland and British Columbia) revealed that up to 85.4% and 91.4% of residents had never been screened with FOBT and endoscopy, respectively. Health regional screening rates (Saskatchewan and Ontario) were also low, with up to 85.5% and 90.8% of the population having never been screened with FOBT and endoscopy, respectively. The large geographical variation echoes findings from one Alberta-based study[21] and several US studies that show large regional and state level differences in CRC test use.[22,23] Geographical variation in use of health preventive services is evident for other types of screening in Canada. Health regional rates of the Papanicolaou (Pap) test in Ontario reportedly vary from 12% to 74%,[24] while across Canada provincial rates vary between 70% to 88%.[25] Similarly, survey data indicate that Canadian provincial breast cancer screening rates vary from approximately 9% in Nunavut to 67% in New Brunswick.[25]

CRC screening rates varied by age as well. People 65 years of age and older were screened more often by both FOBT and endoscopy compared to their younger counterparts, similar to the findings of others.[26-34] Individuals aged 50 to 59 were less likely to report CRC screening, suggesting a delayed uptake of CRC screening recommendations by either or both physicians and younger patients, since at the time of the survey no CRC screening programs were in place. Furthermore, FOBT and endoscopy screening declined in the 80 to 89 year age group and, for endoscopy, dropped off dramatically in the 90 to 100 year age group. These findings may reflect the cost-effective model proposed for the Canadian population, which recommends to stop screening at age 74.[3,35]

No meaningful differences were found in CRC screening rates according to urban vs. rural residence, suggesting that variation in screening was not due to availability of health care resources. One might have expected that rural areas would have been disadvantaged in terms of accessibility to sigmoidoscopy and colonoscopy and, consequently, more likely to have employed FOBT, which is readily available. Our finding corroborates that reported by another Canadian similar study that found CRC procedure rates in rural and urban areas.[21] One possible explanation for the lack of variability between residential areas may rest in regional similarities in physician practice style. Since both FOBT and endoscopy are considered primary screening modalities, physicians who adhere to endoscopy screening may recommend endoscopy regardless of whether facilities are located outside of the patient's residential area.

Rates of FOBT increased moderately between 1 to 2 years ago and the past year, while rates of endoscopy increased almost 6-fold in the past decade. Not only do these trends indicate a steady rise in CRC screening, they may also depict a shift from FOBT to endoscopy for primary CRC screening.[21,34,36-39] These findings should alert decision- and policy-makers of an impending increased demand for screening endoscopy, since at the present time there are insufficient resources to meet that demand.[35]

TABLE 4

Endoscopy screening rates by time interval according to socio-demographic, clinical and geographical characteristics (n^a = 13 949)

Characteristic	Last reported endoscopy screening[b]											
	0 to 5 years			6 to 10 years			10+ years			never		
OVERALL	Rate	95% CI		Rate	95% CI		Rate	95% CI		Rate	95% CI	
	8.8	8.2	9.5	1.5	1.2	1.8	1.0	0.8	1.2	88.7	88.0	89.4
Sex												
male	9.0	8.0	10.0	1.3	0.9	1.7	1.1	0.7	1.5	88.7	87.6	89.7
female	8.7	7.8	9.6	1.7	1.3	2.1	0.9	0.7	1.2	88.7	87.7	89.7
Age (years)												
50 to 64	8.1	7.3	9.0	1.1	0.8	1.5	0.6	0.4	0.9	90.1	89.2	91.0
65+	10.0	8.9	11.0	2.0	1.6	2.5	1.6	1.2	2.0	86.5	85.3	87.6
50 to 59	7.3	6.4	8.3	1.0	0.7	1.4	0.5	0.3	0.8	91.1	90.1	92.2
60 to 69	10.4	9.2	11.6	1.8	1.2	2.4	1.0	0.6	1.4	86.9	85.6	88.2
70 to 79	10.3	8.8	11.8	2.1	1.6	2.7	1.7	0.9	2.4	86.0	84.3	87.7
80 to 89	9.7	6.6	12.8	1.6	0.7	2.5	2.1	1.3	3.0	86.6	83.4	89.8
90 to 100	2.7	n/a	5.7	n/a	n/a	n/a	n/a	n/a	n/a	94.6	90.5	98.8
Residential area												
urban	9.0	8.2	9.8	1.5	1.2	1.8	0.9	0.7	1.1	88.6	87.7	89.4
rural	8.2	7.1	9.4	1.4	0.9	1.9	1.2	0.6	1.9	89.1	87.8	90.4
Education												
< high school	8.2	7.1	9.2	1.6	1.1	2.0	1.0	0.6	1.4	89.3	88.1	90.6
high school grad.	8.4	6.8	10.0	1.3	0.7	1.9	1.0	0.5	1.4	89.3	87.6	91.1
post high school	10.8	7.6	13.9	2.6	0.5	4.7	1.7	n/a	3.7	84.9	81.3	88.6
post high school grad.	9.3	8.2	10.4	1.4	1.0	1.8	0.9	0.7	1.2	88.4	87.2	89.5
Household income												
low to low medium	8.8	7.5	10.2	1.6	1.1	2.0	1.2	0.8	1.7	88.4	87.0	89.8
upper medium	8.5	7.4	9.6	1.7	1.2	2.1	1.1	0.6	1.6	88.7	87.5	90.0
high	9.1	7.7	10.4	1.5	0.8	2.2	0.7	0.4	1.0	88.7	87.2	90.2
Bowel disease												
yes	23.2	16.5	29.9	4.1	1.6	6.6	n/a	n/a	n/a	71.0	63.7	78.2
no	8.6	7.9	9.2	1.4	1.2	1.7	1.0	0.8	1.2	89.0	88.3	89.7
Residential province[c]												
Newfoundland & Labrador	9.0	7.3	10.8	1.7	0.7	2.7	1.2	0.5	2.0	88.1	86.1	90.0
British Columbia	6.5	5.7	7.4	1.2	0.8	1.6	0.8	0.5	1.2	91.4	90.5	92.4

Percentages represent weighted data

[a] Number of respondents providing information on endoscopy screening and representing 2 029 620 Canadians

Rates are based on valid responses (excludes missing values)

[b] Respondents categorized according to the last reported date of screening endoscopy (sigmoidoscopy or colonoscopy)

Endoscopies performed for non-screening purposes are excluded

[c] Ontario and Saskatchewan provincial rates are not reported because data are not available for all health regions

n/a = not available because non-weighted data cells contained less than 5 individuals (Statistics Canada privacy protection regulation)

TABLE 5
Frequency of the three adherence outcomes

Outcome	n	%[a]
Adherence to FOBT screening guidelines[b]		
yes	356 535	15.1
no	2 005 605	84.9
Adherence to endoscopy screening guidelines[c]		
yes	490 128	20.6
no	1 890 047	79.4
Adherence to current CRC screening guidelines[d]		
yes	720 899	30.1
no[e]	1 673 225	69.9

All numbers are weighted

Includes procedures for all indications

[a] Based on valid responses (excludes missing values)

[b] Reported use in the past 2 years for 16 545 respondents (1.3% missing values)

[c] Reported use in the past 10 years for 16 648 respondents (0.6% missing values)

[d] Reported use of FOBT in the past 2 years or endoscopy in the past 10 years for 16 747 respondents

[e] Includes 1.3% of respondents classified according to only one procedure

FIGURE 2.
Health regional rates of adherence to FOBT screening guidelines[*]

[*] Utilization of FOBT in the past 2 years

FIGURE 3
Health regional rates of never-use of FOBT

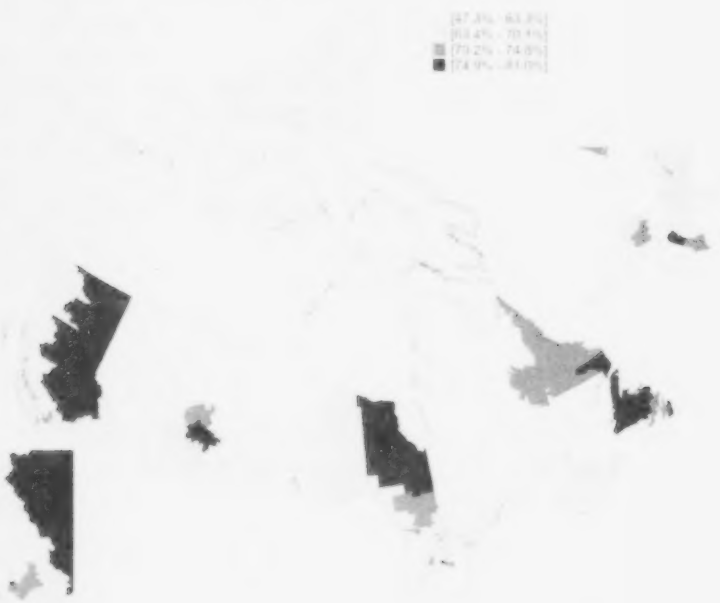
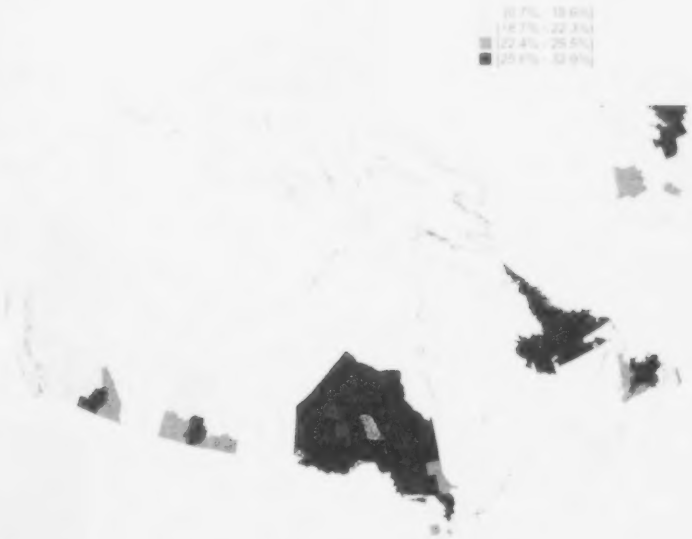


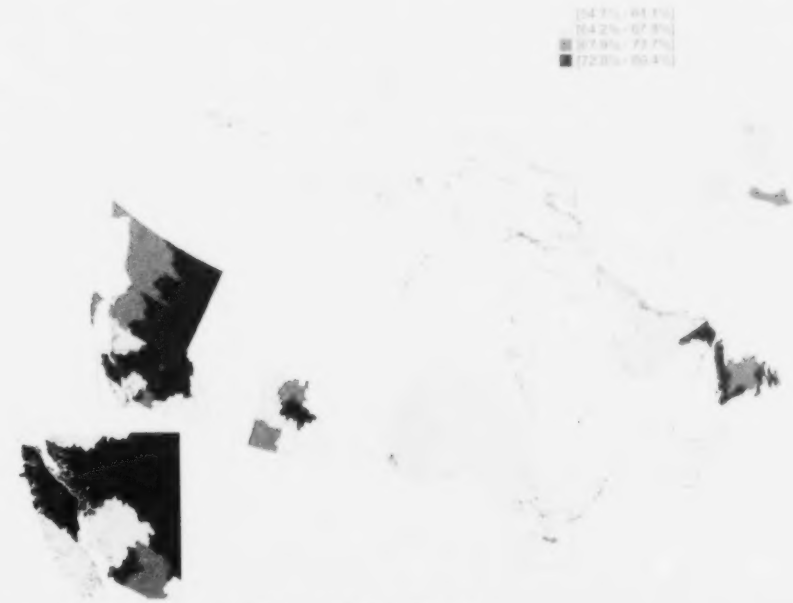
FIGURE 4
Health regional rates of adherence to endoscopy screening guidelines*



*Utilization of sigmoidoscopy or colonoscopy in the past 10 years

FIGURE 5
Health regional rates of never-use of endoscopy

FIGURE 6
Health regional rates of non-adherence to current colorectal-cancer screening guidelines*



*Non-use of FOBT in the past 2 years and endoscopy in the past 10 years

In Canada in 2003, 78.4% and 88.7% of respondents had never been screened by either FOBT or endoscopy, respectively. These findings mirror those of US population-based studies that found that up to 65% of individuals had never received either of these exams[7,11,36] and of one Canadian study that reported that up to 77% had never been screened for CRC.[14] Likewise, in a 6-year follow-up study of Ontario beneficiaries, nearly 80% of CRC screen-eligible individuals aged 50 to 59 years did not receive any large bowel evaluation.[12] Not only do our findings point to the gross underuse of CRC screening, they also convey the message that CRC screening rates are considerably lower than those for either breast or cervical cancer.[8,37,40] In 2003, the proportion of screen-eligible women who underwent guideline-recommended screening was 79% for Pap test and 61% for mammography, the latter increasing from 53% in 2001.[25] The rise in breast-cancer screening rates may be explained by the increasing number of enrollees in provincially organized breast-cancer screening programs, which have been adopted by all Canadian provinces.[41] Multimodal endeavors that proved effective for improving breast-cancer screening rates may be effective at boosting rates of CRC screening. Undoubtedly, providing CRC screening within the context of an organized program may prove to be advantageous by promoting awareness of CRC screening, especially in the younger age group, and monitoring guideline-recommended CRC screening in average-risk Canadians.

Several limitations and strengths are important to consider when interpreting our findings. Endoscopy screening rates may have been overestimated if respondents with bowel disease indicated a screening procedure: since inflammatory bowel disease is a risk factor for the development of CRC, affected individuals are advised to undergo surveillance colonoscopy at more frequent time intervals compared to those considered at average-risk. However, this would not have meaningfully affected the rates of screening because less than 1% of the study population would have been misclassified (3.6% of respondents with bowel disease, of which 23% had a screening endoscopy in the past 5 years). Adherence to endoscopy screening guidelines may have been overestimated if individuals who underwent sigmoidoscopy beyond the recommended 5 years were included. Adherence to current CRC screening guidelines may have been underestimated as 1.3% of respondents were classified as non-adherent based on only one procedure. CRC screening rates may have been slightly underestimated as some of the 50-year-old respondents who reported not being screened at survey time may have been screened before the end of their 50th year. Given the large variability by geographic location, results are likely not generalizable to Canadian provinces for which CRC screening data were not available.

Determining the extent to which CRC screening is performed nationally is methodologically challenging. Whereas administrative database studies cannot distinguish screening exams from those that are performed for other indications, surveys such as the CCHS Cycle 2.1 include responses that permit the determining of the indication for undergoing the procedure. In contrast, surveys that rely on self-report may be problematic for distinguishing sigmoidoscopy from colonoscopy. However, good sensitivity and specificity for self-reported use are found when the two procedures are grouped together,[42-44] as was done in the CCHS.

Study strengths include 1) defining adherence to current CRC screening guidelines according to both FOBT and endoscopy, which provides a snapshot of the proportion of the population that has undergone CRC screening; and 2) determining outcomes in a population where over 96% are at average-risk for the development of CRC. Finally, rates by geographical location are likely to remain stable over short time intervals given that only 4.1% of Canadians aged 45 and over move out of province each year.[44] Because this study used data from 2003 and awareness of CRC screening has increased substantially in the last few years, current CRC screening rates are likely higher than those reported.

Conclusion

In summary, most average-risk respondents had never been screened for CRC by either FOBT or endoscopy, with close to 70% being non-adherent to current screening guidelines. Higher rates of non-adherence to CRC screening guidelines in those aged 50 to 59 suggest delayed uptake of CRC screening recommendations by physicians and younger, average-risk Canadians. It is unclear why screening rates were lower in most regions of British Columbia. Greater use of endoscopy compared to FOBT suggests that it may be used increasingly as a primary CRC screening strategy. The absence of an urban vs. rural difference suggests that a lack of resources in rural areas is not impeding CRC screening. The very low screening rates found in this study coupled with the evidence that CRC screening can reduce incidence of and mortality from CRC suggest that multimodal efforts are needed to increase Canadians' awareness and use of CRC screening.

Acknowledgments

This research was supported by a grant from the Canadian Institutes for Health Research (CIHR), MOP 77666.

Maida J. Sewitch, PhD, is supported as a Research Scientist of the Canadian Cancer Society through an award from the National Cancer Institute of Canada.

Ethical approval from the Research Ethics Board of the Research Institute of the McGill University Health Centre and permission from Statistics Canada were obtained prior to study inception.

References

1. Canadian Cancer Society/National Cancer Institute of Canada. Canadian Cancer Statistics, 2008. Toronto, 2008.

2. Public Health Agency of Canada. Reducing Canadian colorectal cancer mortality through screening. 2002. URL: http://www.phac-aspc.gc.ca/publicat/ncccs-cndcc/ccsrec-eng.php.

3. Leddin D. The Canadian Association of Gastroenterology position on colon cancer screening. Can J Gastroenterol. 2003;17(2):133-134.

4. Canadian Cancer Society. Screening for colorectal cancer. 2004. URL: http://www.cancer.ca/ccs/internet/standard/0,3182,3649_10175_74549480_langId-en,00.html.

5. U.S. Preventive Services Task Force. Screening for colorectal cancer: recommendations and rationale. Ann Intern Med. 2002;137(2):129-131.

6. Winawer S, Fletcher R, Rex D et al. Colorectal cancer screening and surveillance: clinical guidelines and rationale-update based on new evidence. Gastroenterology. 2003;124:544-560.

7. Ata A, Elzey JD, Insaf TZ, Grau AM, Stain SC, Ahmed NU. Colorectal cancer prevention: adherence patterns and correlates of tests done for screening purposes within United States populations. Cancer Detect Prev. 2006;30(2):134-143.

8. Increased use of colorectal cancer tests - United States, 2002 and 2004. MMWR Morb Mortal Wkly Rep. 2006;55(11):308-311.

9. McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. N Engl J Med. 2003;348(26):2635-2645.

10. Etzioni DA, Ponce NA, Babey SH et al. A population-based study of colorectal cancer test use: results from the 2001 California Health Interview Survey. Cancer. 2004;101(11):2523-2532.

11. McQueen A, Vernon SA, Meissner HI, Klabunde CN. Are there gender differences in colorectal cancer test use prevalence and correlates? Cancer Epidemiology, Biomarkers & Prevention. 2006;15(4):782-791.

12. Rabeneck L, Paszat LF. A population-based estimate of the extent of colorectal cancer screening in Ontario. Am J Gastroenterol. 2004;99(6):1141-1144.

13. Vinden C, Schultz S, Rabeneck L. ICES Research Atlas: Use of Large Bowel Procedures in Ontario. Toronto, ON: Institute for Clinical Evaluative Sciences (ICES), 2004.

14. Ramji F, Cotterchio M, Manno M, Rabeneck L, Gallinger S. Association between subject factors and colorectal cancer screening participation in Ontario, Canada. Cancer Detection and Prevention. 2005;29(3):221-226.

15. McGregor SE, Hilsden RJ, Li FX, Bryant HE, Murray A. Low uptake of colorectal cancer screening 3 years after release of national recommendations for screening. Am J Gastroenterol. 2007;102(8):1727-1735.

16. Statistics Canada. Canadian Community Health Survey Cycle 2.1. 2003. URL:http://www.statcan.ca/english/concepts/health/cycle2_1/cchsinfo.htm.

17. Statistics Canada. The Canadian Community Health Survey, Cycle 2.1. 2002.

18. Statistics Canada. Health regions: Boundaries and correspondence with census geography. 2003. Catalogue no. 82-402-XIE.

19. Statistics Canada. Canadian Community Health Survey 2003: User Guide for the Public Use Microdata File of 2005:22-32.

20. SAS Version 8.02. Cary, North Carolina, USA, 2001.

21. Hilsden RJ. Patterns of use of flexible sigmoidoscopy, colonoscopy and gastroscopy: a population-based study in a Canadian province. Can J Gastroenterol. 2004;18(4):213-2119.

22. Ko CW, Kreuter W, Baldwin L-M. Persistent demographic differences in colorectal cancer screening utilization despite Medicare reimbursement. BMC Gastroenterol. 2005;5(1):10.

23. Cooper GS, Koroukian SM. Geographic variation among Medicare beneficiaries in the use of colorectal carcinoma screening procedures. Am J Gastroenterol. 2004;99(8):1544-1550.

24. Fehringer G, Howlett R, Cotterchio M, Klar N, Majpruz-Moat V, Mai V. Comparison of papanicolaou (Pap) test rates across Ontario and factors associated with cervical screening. Can J Public Health. 2005;96(2):140-144.

25. Canadian Cancer Society/National Cancer Institute of Canada. Canadian Cancer Statistics 2006.

26. Lemon S, Zapka J, Luckmann R, Chasan-Taber L. Colorectal cancer screening participation: comparisons with mammography and prostate-specific antigen screening. Am J Pub Health. 2001;91(8):1264-1272.

27. Cokkinides VE, Chao A, Smith RA, Vernon SW, Thun MJ. Correlates of underutilization of colorectal cancer screening among U.S. adults, age 50 years and older. Prev Med. 2003;36(1):85-91.

28. Nadel MR, Blackman DK, Shapiro JA, Seeff LC. Are people being screened for colorectal cancer as recommended? Results from the National Health Interview Survey. Prev Med. 2002;35(3):199-206.

29. Walsh JME, Posner SF, Perez-Stable J. Colon cancer screening in the ambulatory setting. Prev Med. 2002;35(3):209-218.

30. Thompson B, Coronado GD, Solomon CC, McClerran DF, Neuhouser ML, Feng Z. Cancer prevention behaviours and socioeconomic status among Hispanics and non-Hispanic whites in a rural population in the United States. Cancer Causes and Control. 2002;13(8):719-728.

31. Brawarsky P, Brooks DR, Mucci LA. Correlates of colorectal cancer testing in Massachusetts men and women. Prev Med. 2003;36(6):659-668.

32. Ioannou GN, Chapko MK, Dominitz JA. Predictors of colorectal cancer screening participation in the United States. Am J Gastroenterol. 2003;98(9):2082-2091.

33. Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients. Factors associated with screening behavior. Am J Prev Med. 2003;25(3):187-194.

34. Harewood GC, Lieberman DA. Colonoscopy practice patterns since introduction of Medicare coverage for average-risk screening. Clin Gastroenterol Hepatol. 2004;2(1):72-77.

35. Flanagan WM, LePetit C, Berthelot JM, White KJ, Coombs BA, Jones-McLean E. Potential impact of population-based colorectal cancer screening in Canada. Chronic Dis Can. 2003;24(4):81-88.

36. Colorectal cancer test use among persons aged > or = 50 years – United States, 2001. MMWR Morb Mortal Wkly Rep. 2003; 52(10):193-196.

37. Swan J, Breen N, Coates RJ, Rimer BK, Lee NC. Progress in cancer screening practices in the United States. Results from the 2000 National Health Interview Survey. Cancer. 2003;97(6):1528-1540.

38. Robertson RH, Burkhardt JH, Powell MP, Eloubeidi MA, Pisu M, Weissman NW. Trends in colon cancer screening procedures in the US Medicare and Tricare populations: 1999-2001. Prev Med 2006;42(6):460-462.

39. Meissnner HI, Breen N, Klabunde CN, Vernon SW. Patterns of colorectal cancer screening uptake among men and women in the United States. Cancer Epidemiology, Biomarkers & Prevention 2006;15(2):389-394.

40. Miedema BB, Tatemichi S. Breast and cervical cancer screening for women between 50 and 69 years of age: what prompts women to screen? Womens Health Issues. 2003;13(5):180-184.

41. Wadden N, Doyle GP. Breast cancer screening in Canada: a review. Can Assoc Radiol J. 2005;56(5):271-275.

42. Baier M, Calonge N, Cutter G et al. Validity of self-reported colorectal cancer screening behavior. Cancer Epidemiology, Biomarkers & Prevention. 2000;9(2):229-232.

43. Madlensky L, McLaughlin J, Goel V. A comparison of self-reported colorectal screening with medical records. Cancer Epidemiology, Biomarkers & Prevention. 2003;12(7):656-659.

44. Statistics Canada. Population 1 year and over by age groups, showing mobility status (place of residence 1 year ago), for Canada, provinces and territories, 1996 census (20% sample data). URL: http://www.statcan.ca/english/census96/apr14/mob2.htm.

Stroke surveillance in Manitoba, Canada: Estimates from administrative databases

DF Moore, MD, PhD (1); LM Lix, PhD (2); MS Yogendran, MSc (3); P Martens, PhD (3); A Tamayo, MD (4)

Abstract

This study investigated the use of population-based administrative databases for stroke surveillance. First, a meta-analysis was conducted of four studies, identified via a PubMed search, which estimated the sensitivity and specificity of hospital data for ascertaining cases of stroke when clinical registries or medical charts were the gold standard. Subsequently, case-ascertainment algorithms based on hospital, physician and prescription drug records were developed and applied to Manitoba's administrative data, and prevalence estimates were obtained for fiscal years 1995/96 to 2003/04 by age group, sex, region of residence and income quintile. The meta-analysis results revealed some over-ascertainment of stroke cases from hospital data when the algorithm was based on diagnosis codes for any type of cerebrovascular disease (Mantel-Haenszel Odds-Ratio [OR] = 1.70 [95% confidence interval (CI): 1.53 – 1.88]). Analyses of Manitoba administrative data revealed that while the total number of stroke cases varied substantially across the algorithms, the trend in prevalence was stable regardless of the algorithm adopted.

Key words: *administrative data, surveillance, population health, stroke, longitudinal, diagnoses*

Introduction

Death due to stroke is ranked third in Canada and in other developed countries after heart diseases and cancer, while the stroke burden and case fatality rate is estimated to eclipse that of other chronic diseases.[1-3] Despite advances in acute stroke care, prevention of stroke-related risk factors is likely to remain the most effective mechanism to reduce the disease burden.[4] Population-based surveillance allows researchers and policy analysts to describe the disease burden for population groups defined by such characteristics as age, sex, region of residence and income level. Surveillance can also facilitate assessments of the effectiveness of risk prevention strategies over time. Large-scale administrative databases have been used for population-based surveillance of a number of chronic conditions, including stroke.[5,6] The advantages of administrative data include: (a) ability to generalize prevalence estimates to the whole population rather than just to specific sub-populations, (b) lower costs associated with establishment and maintenance of a surveillance system,[7] (c) ability to monitor trends in prevalence, and (d) opportunity to investigate associated co-morbidities.[7]

Hospital administrative data have often been used to identify stroke cases in the population, but there has been only limited investigation of physician billing claims for this purpose.[8-12] The choice of diagnosis codes to identify stroke cases has been a critical issue in the development of case-ascertainment algorithms using administrative data. An algorithm based on diagnostic codes for all forms of cerebrovascular disease will have improved sensitivity, but could result in possible over-ascertainment of stroke cases when compared with a clinical data source. An algorithm based on a narrower set of diagnostic codes will have improved specificity, but may result in conservative estimates of the number of stroke cases.[13,14] In the medical literature, ischemic stroke is often classified according to the TOAST (Trial of ORG 10172 in Acute Stroke Treatment) criteria.[15-17] This classification better defines the aetiology of ischemic stroke by focusing on clinical treatment strategies such as the use of warfarin for cardio-embolic stroke or anti-platelet therapy for large and small vessel disease.

At present, no studies have extended the methodology of stroke case ascertainment to include data from population-based prescription drug dispensation records,[7] which are now routinely maintained in a number of jurisdictions. It is possible that the combination of three data sources – hospital separations, physician billing claims, and prescription drug records – may improve stroke case ascertainment.[18,19] In fact, in one study of six chronic diseases (hypertension, heart failure, chronic lung disease, arthritis, glaucoma and diabetes), the use of multiple administrative databases to ascertain disease cases resulted in specificity greater than 0.95 and sensitivity greater than 0.90 when compared with an independent validation data source.[20]

In the current study we begin by using meta-analysis techniques to assess the validity of diagnoses in administrative data for stroke case ascertainment. We then apply the meta-analysis results to develop case-ascertainment algorithms based on

Author References

1 Walter Reed Army Medical Center, Washington, DC
2 School of Public Health, University of Saskatchewan, Saskatoon, SK
3 Manitoba Centre for Health Policy, University of Manitoba, Winnipeg, MB
4 Brandon Regional Health Authority, Brandon, MB
Correspondence: Lisa M. Lix, School of Public Health, University of Saskatchewan, Health Sciences Building, 107 Wiggins Road, Saskatoon SK S7N 5E5, Tel.: 306-966-1617, Email: lisa.lix@usask.ca

diagnoses in hospital and physician data as well as records of dispensations for prescription drugs used in the treatment of stroke. The algorithms are applied to administrative data from Manitoba, Canada, to estimate the prevalence of stroke by age, sex, region of residence and income group over time.

Methods

Meta-analysis of stroke case ascertainment

A comprehensive PubMed search on the terms administrative database **AND** stroke **OR** cerebrovascular disease identified a total of 28 references for the period 1965-2005. After full review of these articles by the first author, four were selected for investigation using meta-analytic techniques. All of the selected studies used a "gold standard", that is, an independently maintained stroke registry or a prospective or retrospective chart review to validate administrative data for stroke case ascertainment. The studies selected for the meta-analysis relied on hospital data in which diagnoses were coded using the International Classification of Diseases, 9th revision (ICD-9). Studies excluded from the meta-analysis did not validate the administrative data, did not use ICD-9 codes to ascertain disease cases, and/or did not disclose the information necessary to construct a 2 x 2 classification table composed of the number of stroke cases and non-cases in the administrative and validation datasets.

The studies selected for the meta-analysis identified acute stroke cases using a "sensitive" algorithm based on all diagnosis codes for cerebrovascular disease (i.e. ICD-9-CM 430 to 438) and/or a "specific" algorithm based on a subset of ICD-9-CM codes most likely to identify only acute stroke cases in administrative data.

Odds ratios (ORs) were calculated for each of the studies included in the meta-analysis for the sensitive and specific algorithms. Pooled odds ratios were calculated for the sensitive and specific algorithms using the Mantel-Haenszel method.[21,22] The pooled ORs were based on three datasets for the sensitive algorithm and four datasets for the specific algorithm. An OR = 1.0 indicates that the probability of the event (i.e. stroke case ascertainment) is equally likely in both the administrative data and validation data source. An OR > 1.0 indicates an overestimate of stroke ascertainment by the administrative data compared to the validation data source while an OR < 1.0 indicates that stroke case ascertainment is lower in administrative data than in the validation data source. The meta-analysis was conducted using SAS software.[23]

Stroke case ascertainment in Manitoba's administrative data

The Research Data Repository housed at the Manitoba Centre for Health Policy (MCHP) was used to estimate stroke prevalence for sensitive and specific case-ascertainment algorithms. The Repository has been used in many studies of population health and health services use.[24,25]

MCHP maintains comprehensive population-based administrative data, including hospital separations, physician billing claims, and out-patient prescription drug dispensation records, for all health insurance registrants.[5] The Manitoba population is approximately 1.2 million according to Statistics Canada Census figures.[26] Nonparticipation in the provincial health insurance program is minimal since no premium payment requirement exists.[5] Administrative data files in the Repository can be linked over time via a unique anonymized personal health identification number (PHIN). Demographic information for health insurance registrants, including age, sex and geographic location of residence is available in the Repository by linking to the population registry. As well, income groups have been derived by linking the Repository data to data for dissemination areas. These are the smallest geographic areas for which Statistics Canada Census data are provided.

A hospital separation abstract is completed at the point of discharge from an acute care facility; each abstract contains up to 16 diagnosis codes. Physician billing claims contain a single diagnosis code. A small number of physicians in Manitoba are salaried; however, most of them submit "shadow billing claims" for billing purposes. It has been estimated that shadow billing results in at least 80% capture of services (Katz A., personal communication, February 2007). Diagnoses in hospital and physician data are recorded using ICD-9-CM codes up to fiscal year 2003/04, but commencing in fiscal year 2004/05, ICD-10-CA coding was introduced in hospital separations.

The Drug Programs Information Network (DPIN) is an on-line point-of-sale prescription drug database linking all retail pharmacies in Manitoba. DPIN captures prescription drug dispensations for all Manitoban residents regardless of coverage mechanism. Prescription drugs are identified via drug identification numbers (DINs) which are linked to the Drug Product Database maintained by Health Canada. Anatomic Therapeutic Chemical (ATC) codes[27] are added to allow categorization of drugs into appropriate therapeutic and pharmacological subgroups.

All 16 diagnosis fields in a hospital separation abstract were searched to identify stroke cases. Table 1 lists ICD-9-CM codes for cerebrovascular disease, the stroke type to which each code corresponds, and its relationship to the TOAST criteria. Using TOAST, ischemic stroke is categorized as stroke related to (a) large artery atherosclerosis (including large artery thrombosis and artery-to-artery embolism), (b) cardioembolism, (c) small artery occlusion, (d) stroke of other determined cause, and/or (e) stroke of undetermined cause. The TOAST cardio-embolic stroke category cannot be identified from ICD-9-CM codes.

After reviewing the literature and consulting with clinical experts, the authors selected the following drug categories for identification of stroke cases from the DPIN data: (a) *anti-platelet agents* such as aspirin (ASA) at 81 or 325 mg once a day, clopidogrel, ticlopidine, dipyridamole and combination agents such as Aggrenox (ASA 25 mg dipyridamole 200 mg slow release) and (b) *oral anti-coagulants* such as warfarin, phenindione, and nicoumalone. The ATC codes (fifth level) were B01AA02, B01AA03, B01AA07, B01AC07, B01AB01, B01AC30, B01AC05, B01AC06, B01AC04, B01AB09, B01AB04, B01AB10. Thrombolytic agents such as rt-PA (recombinant tissue plasminogen activator) and intravenous anti-platelet agents (anti GP 2b/3a) such as

abciximab, tirofiban and eptifibatide cannot be identified in DPIN data.

Stroke cases were identified by the following rules: at least one hospital separation in one fiscal year (i.e. 1 + H), or at least two ICD-9-CM physician billing claims in one fiscal year (i.e. 2 + P), or at least one physician billing claim in one fiscal year together with at least two prescription drug records in one fiscal year (i.e. 1 + P and 2 + Rx). Case counts were derived for each of the fiscal years 1995/96 to 2003/04. The fiscal year extends from April 1 to March 31 of the following year. This time period was chosen because in 1994/95 the DPIN system originated, while in 2004/05 ICD-10-CA coding was introduced. Consistency was therefore maintained by the yearly application of a case-ascertainment algorithm based on ICD-9-CM codes.

Frequencies of stroke cases were compiled for both sensitive and specific algorithms by study year, age group (19 to 44, 45 to 54, 55 to 64, 65 to 74, 75 to 84, 85 years and older), sex, region of residence (Northern Regional Health Authorities, Southern Regional Health Authorities and Winnipeg Regional Health Authority, with the Regional Health Authority representing the health administrative unit of the province) and income quintile (Q1 to Q5, with Q1 representing the lowest income group). The geographic areas broadly correspond to sparsely populated rural, rural, and urban communities. Individuals were assigned to income quintiles using average household income data for dissemination areas, and then ranked according to these areas. The quintiles are defined so that approximately 20% of the total population is assigned to each group.[24] Income quintiles are defined separately for urban and rural areas. Prevalence estimates were calculated using data from the provincial registry to compute the denominator of the estimate.

Regression analyses were conducted to test for differences in the relative rate (RR) of stroke for different population sub-groups and over time. The data for each study year were first analyzed using generalized linear models[25] to relate stroke counts to the main effects of age group, sex, region of residence, income quintile and algorithm (i.e. sensitive, specific), as well as selected two-way interactions among these variables. To ensure a parsimonious model, only those interactions that resulted in a significant improvement in model fit, as evaluated with a likelihood ratio test, were retained. An offset, the log of the total population, was included in all models. The data were initially parameterized using Poisson, negative binomial and gamma distributions. Goodness-of-fit statistics were compared, and the distribution resulting in the best fitting model was selected. The longitudinal data were analyzed using a generalized linear model with generalized estimating equations (GEEs) to account for correlation among the stroke case counts over time.[25] The main effects of age group, sex, region of residence, income quintile, algorithm and year/time were included in the model. Selected two-way interactions were included, but these model effects were only retained if they resulted in a significant improvement in model fit. Again, the data were initially parameterized using Poisson, negative binomial and gamma distributions, and goodness-of-fit statistics were compared. The correlation structure was chosen to be exchangeable after examination of the sample correlation matrix. The regression analyses were conducted using SAS software.[23]

TABLE 1

ICD-9-CM codes for ascertaining cases of stroke in administrative data, relationship to TOAST criteria and frequency in Manitoba hospital separations, 1995/96 to 2003/04

ICD-9-CM Code	Stroke Type	TOAST Criterion	Freq[b]	%
430	Subarachnoid hemorrhage	N/A[a]	901	1.7
431	Cerebral hemorrhage	N/A	2038	4.0
432	Other and unspecified intracranial hemorrhage	N/A	951	1.8
433	Occlusion and stenosis of pre-cerebral arteries	Large vessel disease	5957	11.9
434	Occlusion of cerebral arteries	Large and small vessel disease	5968	11.9
435	Transient cerebral ischemia	N/A	8189	16.3
436	Acute but ill-defined cerebrovascular disease	Stroke of other determined cause	12 061	24.0
437	Other and ill-defined cerebrovascular disease	Stroke of undetermined cause	2667	6.5
438	Late effects of cerebrovascular disease	N/A	12 266	22.4
All			50 098	100.0

[a] N/A = not applicable

[b] Frequencies are the number of individuals (19 years and older) with at least hospital separation having the identified ICD-9-CM code

Results

Meta-analysis of stroke case ascertainment

Table 2 reports the study-specific ORs for stroke case ascertainment from hospital administrative data. The specific algorithm based on the restricted set of ICD-9-CM codes, for which there were three datasets available for analysis, resulted in ORs which were smaller in magnitude and closer to 1.0 than the ORs for the sensitive algorithm based on all diagnosis codes for cerebrovascular disease, for which there were four datasets available for analysis. As Table 2 reveals, the pooled OR for the datasets that used a sensitive algorithm was 1.70 (95% CI: 1.53, 1.88) while the pooled OR for the datasets that used a specific algorithm was 1.02 (95% CI: 0.93, 1.13), indicating some over-ascertainment for the former but not for the latter.

TABLE 2

Odds ratios (ORs) for the meta-analysis of stroke case ascertainment in hospital data for sensitive and specific sets of diagnosis codes

Study	Sensitive Algorithm OR (95% CI)[a]	Specific Algorithm OR (95% CI)[b]
Ellekjaer et al. [32]	1.76 (1.51, 2.05)	1.17 (1.00, 1.38)
Leibson et al. [18]	1.47 (1.17, 1.86)	1.20 (0.95, 1.53)
Reker et al. [33]	1.76 (1.46, 2.10)	0.72 (0.58, 0.89)
Tirschwell et al. [13]	--	1.02 (0.80, 1.31)
Pooled OR	**1.70 (1.53, 1.88)**	**1.02 (0.93, 1.13)**

[a] The sensitive algorithm is based on ICD-9-CM codes 430 to 438 for all studies except for Reker et al. 33 who excluded 437 and 438

[b] The specific algorithm is based on ICD-9-CM codes 430, 431, 434 and 436 for all studies except Reker et al. 33 (excluded 436), Leibson et al. 18 (included 437), and Tirschwell et al. 13 (included 435)

Stroke case ascertainment in Manitoba's administrative data

Table 1 shows the frequency of stroke cases identified from hospital data for each of ICD-9-CM codes 430 to 438 for the period 1995/96 to 2003/04. More than half (54.7%) of cases had non-specific diagnostic codes of 432, 436, 437 and 438.

The frequency of stroke cases from hospital, physician, and pharmacy administrative data is reported next. The number of cases satisfying the 1 + H rule was identified first, followed by the number of cases identified with the 2 + P rule, and then the number of additional cases identified with the 1 + P and 2 + Rx rule. The results are reported separately for the sensitive algorithm based on all diagnoses for cerebrovascular disease in hospital and physician administrative data and the specific algorithm based on a subset of diagnoses most likely to identify acute stroke cases. For the latter, we initially reported the results for two different subsets of ICD-9-CM codes: one set included transient ischemic attacks while the other did not. Only the results for the first specific algorithm are included in subsequent regression analyses.

As Table 3 reveals for the sensitive algorithm, 49.9% of stroke cases were identified from hospital data at the beginning of the study period (i.e. 1995/96); this percentage dropped substantially to 38.5% by the end of the study period. However, the percentage of stroke cases identified solely from physician data remained relatively constant over time. The percentage of cases identified from a combination of physician data and prescription drug data increased over time, from 5.6% in 1995/96 to 15.8% in 2003/04. The same trend of decreasing numbers of stroke cases identified from hospital data and increasing numbers identified from physician and prescription drug data was also observed when the more specific algorithm was adopted.

The crude provincial prevalence estimates (Table 3) are relatively unchanged across time regardless of the algorithm used. However, the rate based on the smallest set of ICD-9-CM codes is approximately half the value of the rate derived using the full set of diagnostic codes for cerebrovascular disease.

Next, the number of stroke cases in each year was analyzed using generalized linear models. The negative binomial distribution provided a better fit to the data than either the Poisson or gamma distributions as judged by the ratio of the residual deviance to the model degrees of freedom. The likelihood ratio test showed that models containing two-way interactions were not a significantly better fit to the data than a simpler model containing main effects only ($p > .05$), thus the latter was retained. The model results for fiscal year 1998/99 are reported in Table 4; similar results were observed for all other years of data and are therefore not reported here. The relative rate (RR) of stroke was significantly lower in both southern rural and urban regions than in northern Manitoba, and significantly higher in older groups. An income gradient was observed, such that the RR of stroke was lower in higher income quintiles. The rate was higher in males than in females, and the rate for the specific algorithm was significantly lower than for the sensitive algorithm.

The longitudinal prevalence data were also modeled. A negative binomial distribution was again selected because it resulted in a better fit to these data than either the gamma or Poisson distributions. The inclusion of year x region and year x age group interaction terms resulted in a significant improvement in model fit; other two-way interaction terms were not retained in the model because they did not significantly improve model fit. For the year x region interaction, the analyses revealed that after adjusting for other model effects, the RR of change in stroke prevalence was greater for southern rural (RR = 1.01, 95% CI = 1.00, 1.02) and for urban (RR = 1.02, 95% CI = 1.01, 1.04) regions than for the northern regions of Manitoba. For the latter, the analyses showed that compared to the 19 to 44 years age group, the RR of change in stroke prevalence was lower for 55 to 64 years (RR = 0.96; 95% CI = 0.95, 0.99), 65 to 74 years (RR = 0.96; 95% CI = 0.94, 0.97), 75 to 84 years (RR = 0.95; 95% CI = 0.94, 0.97), and 85+ years (RR = 0.96; 95% CI = 0.94, 0.98). Figures 1 and 2 illustrate the nature of the trends in prevalence estimates for age groups and regions. Main effects of sex, income quintile and algorithm were also significant ($p < 0.05$), and the RR estimates were similar to those reported in Table 4.

Discussion

This study builds on previous research that has explored the potential role of administrative data for stroke surveillance. A number of case-ascertainment algorithms were applied to administrative databases available in Canadian provinces and territories. The stroke prevalence estimates were indirectly validated via a meta-analysis of previous studies that compared hospital data to medical chart or registry data. The results of the meta-analysis revealed that the odds of agreement between administrative data and chart or registry data were better when a specific set of diagnostic codes was used instead of a sensitive set of codes.

TABLE 3

Frequency (%) of stroke cases by data source and ICD-9-CM codes and crude prevalence of stroke, 1995/96 – 2003/04

	Hospital* (1 + H)		Physician (2 + P)		Physician + Drug (1 + P & 2 + Rx)		Total	
Fiscal Year	Freq	%	Freq	%	Freq	%	Freq	Prev (%)
Sensitive Algorithm (ICD-9-CM 430 to 438)								
1995/96	4882	49.9	4349	44.5	551	5.6	9782	1.16
1996/97	5053	51.5	4203	42.9	547	5.6	9803	1.16
1997/98	4790	48.7	4339	44.1	701	7.1	9830	1.16
1998/99	4777	48.6	4357	44.3	702	7.1	9836	1.16
1999/00	4488	45.8	4398	44.9	920	9.4	9806	1.16
2000/01	4585	44.3	4587	44.3	1176	11.4	10 348	1.21
2001/02	4276	41.5	4557	44.3	1462	14.2	10 295	1.20
2002/03	3948	39.9	4447	45.0	1488	15.1	9883	1.14
2003/04	3993	38.5	4746	45.7	1635	15.8	10 374	1.19
Specific Algorithm #1 (ICD-9-CM 430, 431, 434, 435, 436)								
1995/96	3283	43.8	3704	49.4	517	6.9	7504	0.89
1996/97	3239	43.8	3573	48.3	584	7.9	7396	0.88
1997/98	3166	42.3	3656	48.9	662	8.8	7484	0.89
1998/99	3234	43.4	3554	47.7	656	8.8	7444	0.88
1999/00	2956	39.9	3603	48.6	855	11.5	7414	0.87
2000/01	2955	37.5	3836	48.7	1084	13.8	7875	0.92
2001/02	2831	36.1	3726	47.5	1281	16.3	7838	0.91
2002/03	2666	35.6	3546	47.4	1275	17.0	7487	0.87
2003/04	2705	33.8	3869	48.4	1422	17.8	7996	0.92
Specific Algorithm #2 (ICD-9-CM 430, 431, 434, 436)								
1995/96	2431	45.1	2518	46.7	439	8.1	5388	0.64
1996/97	2406	45.7	2433	46.2	426	8.1	5265	0.62
1997/98	2281	43.2	2525	47.9	468	8.9	5274	0.62
1998/99	2328	44.1	2478	46.9	475	9.0	5281	0.62
1999/00	2091	40.1	2507	48.1	614	11.8	5212	0.61
2000/01	2197	39.5	2599	46.8	761	13.7	5557	0.65
2001/02	2113	37.7	2601	46.3	898	16.0	5612	0.65
2002/03	2035	37.8	2468	45.9	875	16.3	5378	0.62
2003/04	2023	35.3	2683	46.8	1024	17.9	5730	0.66

* Hospital separations (1 + H) have precedence over physician billing claims (2 + P), which in turn have precedence over combined physician and prescription drug data (1 + P and 2 + Rx) for identification of stroke cases

Examination of the distribution of stroke cases across the diagnosis codes can yield insights into health-care resource requirements. In Manitoba we found that in hospital data, almost 1000 stroke cases per year (i.e. about 16%) are identified as transient ischemic attacks with, by definition, no extended functional neurological deficits. Patients with such events are good candidates for secondary prevention through the correct assessment of cerebrovascular risk factors together with subsequent treatment involving surgery or medical therapy. The number of subarachnoid and cerebral hemorrhages was seen to represent approximately 10% of all stroke cases in Manitoba compared to the usually quoted 20% rate for hemorrhagic stroke in most population studies. While it is likely that coding for hemorrhagic stroke is reliable due to the nature of the clinical encounter, such discrepancies in ascertainment can only really be resolved by validation studies involving direct chart review or by development of an inclusive stroke registry.

The use of physician billing claims and prescription drug records in addition to hospital separations increased the total number of stroke cases identified with Manitoba's administrative data. In fact, the number of identified cases nearly doubled merely by inclusion of the physician billing data. The use of prescription drug records in combination with physician billing claims resulted in identification of a small but increasing number of cases over time.

TABLE 4
Regression analyses of the relative rate (RR) of stroke in Manitoba, 1998/99

Model Effect	Estimate (se)[a,b]	RR (95% CI)[c]
South Rural	-0.27 (0.05)	0.77 (0.70, 0.84)
Winnipeg	-0.25 (0.05)	0.78 (0.71, 0.85)
North Rural	Ref	–
85 years and older	4.54 (0.05)	93.41 (84.92, 102.76)
75-84 years	4.24 (0.05)	69.61 (63.67, 76.10)
65-74 years	3.55 (0.05)	34.97 (31.95, 38.28)
55-64 years	2.72 (0.05)	15.20 (13.83, 16.72)
45-54 years	1.70 (0.05)	4.47 (4.93, 6.06)
19-44 years	Ref	–
Quintile 5	-0.30 (0.03)	0.74 (0.69, 0.79)
Quintile 4	-0.20 (0.03)	0.82 (0.49, 0.62)
Quintile 3	-0.16 (0.03)	0.86 (0.81, 0.91)
Quintile 2	-0.13 (0.03)	0.88 (0.83, 0.93)
Quintile 1	Ref	–
Male	0.23 (0.02)	1.26 (1.21, 1.31)
Female	Ref	–
Specific[d] algorithm	-0.27 (0.02)	0.77 (0.74, 0.80)
Sensitive algorithm	Ref	–

[a] se = standard error

[b] Parameter estimates were obtained using a generalized linear model with a negative binomial distribution

[c] CI = confidence interval

[d] The specific algorithm was based on the following ICD-9-CM codes: 430, 431, 434, 435 and 436

The total number of stroke cases identified with Manitoba's administrative data changed very little over time, although the total number of cases identified with hospital data decreased. This has important implications for future stroke surveillance studies. Use of a single administrative data source could give a misleading picture of changes in stroke prevalence over time.

Analyses of the annual stroke data revealed significant variations across both income groups and geographic areas of Manitoba, even after adjusting for differences in age and sex. The trend analyses showed that the prevalence of stroke decreased slightly across older age groups relative to the youngest age group, but increased slightly across urban and southern rural regions relative to the northern region. Our study results are largely consistent with other epidemiological studies, such as the Framingham study, which shows a greater prevalence of stroke in males compared to females and a stroke burden that is largely unchanged over time.[4] These results have important implications for stroke therapy, post stroke dependency, rehabilitation and the development of targeted stroke prevention programs. For example, thrombolytic therapy in the older age group results in a higher mortality, although this age group has higher mortality than younger age groups even without rt-PA.[30,31]

This study has some limitations. We have estimated the annual prevalence of stroke, but stroke incidence is not investigated. However, the stroke incidence rate can be estimated using the slope of the prevalence trend. The stability of the prevalence estimates over time suggests that incidence remains relatively constant in Manitoba. A complete picture of incidence would, however, use provincial vital statistics data in addition to hospital, physician, and prescription drug data. Like all epidemiological studies, investigations of stroke case ascertainment from administrative databases represent a snapshot of events with an implied estimation error. While estimation error was not quantified in the current study, it was approximated by reporting results for both sensitive and specific algorithms, which likely represent the upper and lower bounds of stroke prevalence.

The data capture all residents of Manitoba having health registration coverage from Manitoba Health in any one year. No attempt was made to eliminate residents who were only partially covered during the fiscal year due to in-province or out-of-province migration, and therefore may have had a lower probability of meeting the criteria required for identification of stroke cases. At the same time, the inclusion of residents with only partial coverage during the fiscal year because of death means that the data represent a better estimate of all stroke cases in Manitoba, not just stroke survivors.

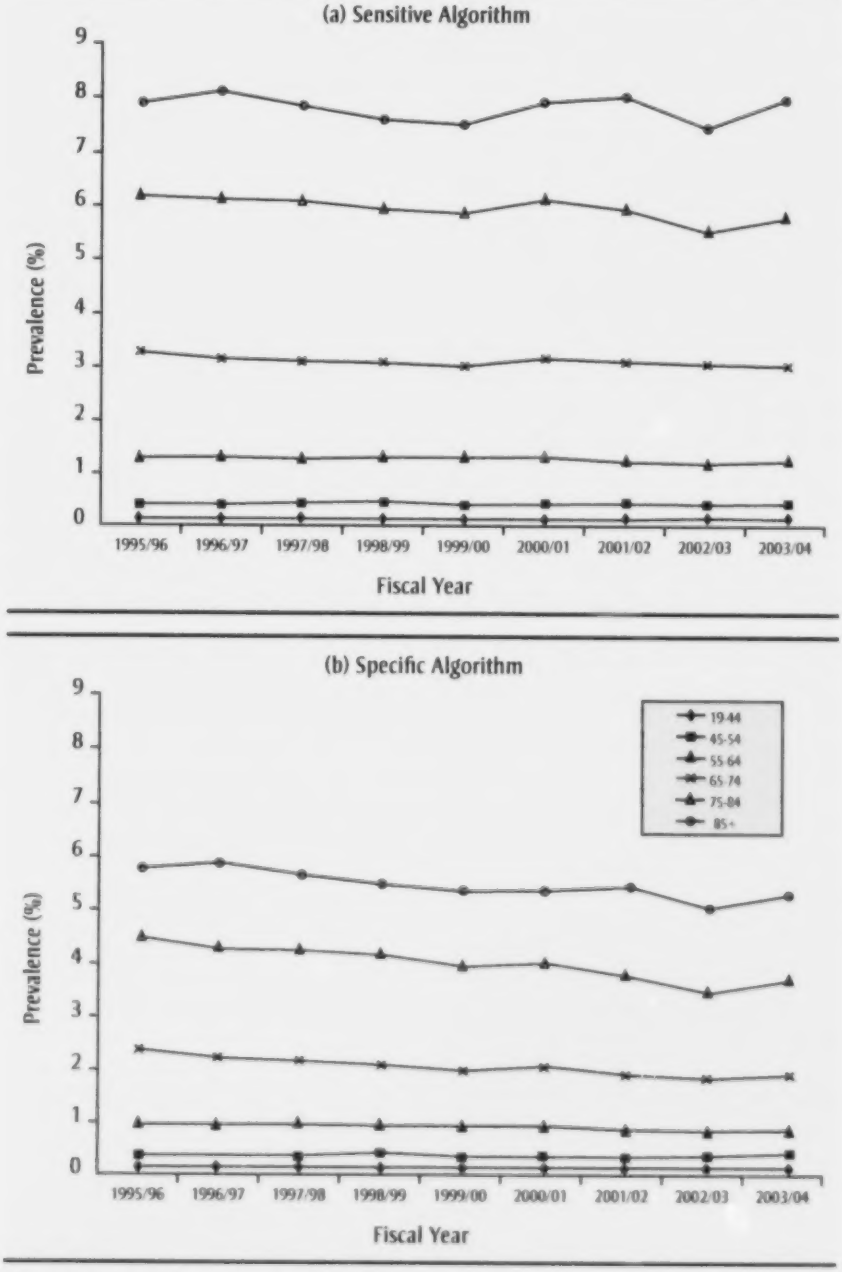
In a recent review of the transition from ICD-9 to ICD-10 coding, no significant difference was found between the two classification systems for stroke case ascertainment or risk factors.[6] However, the effect of the change in coding on stroke case ascertainment in hospital separations warrants further investigation using Manitoba data.

In conclusion, administrative data can be used for population-based surveillance of a variety of chronic conditions, including stroke. Administrative data can be used to describe socio-demographic variations in the population-prevalence of stroke and to conduct retrospective studies of change over time. These data represent a cost-effective tool for providing information about the burden of stroke on the population and for informing health policy decisions.

Acknowledgements

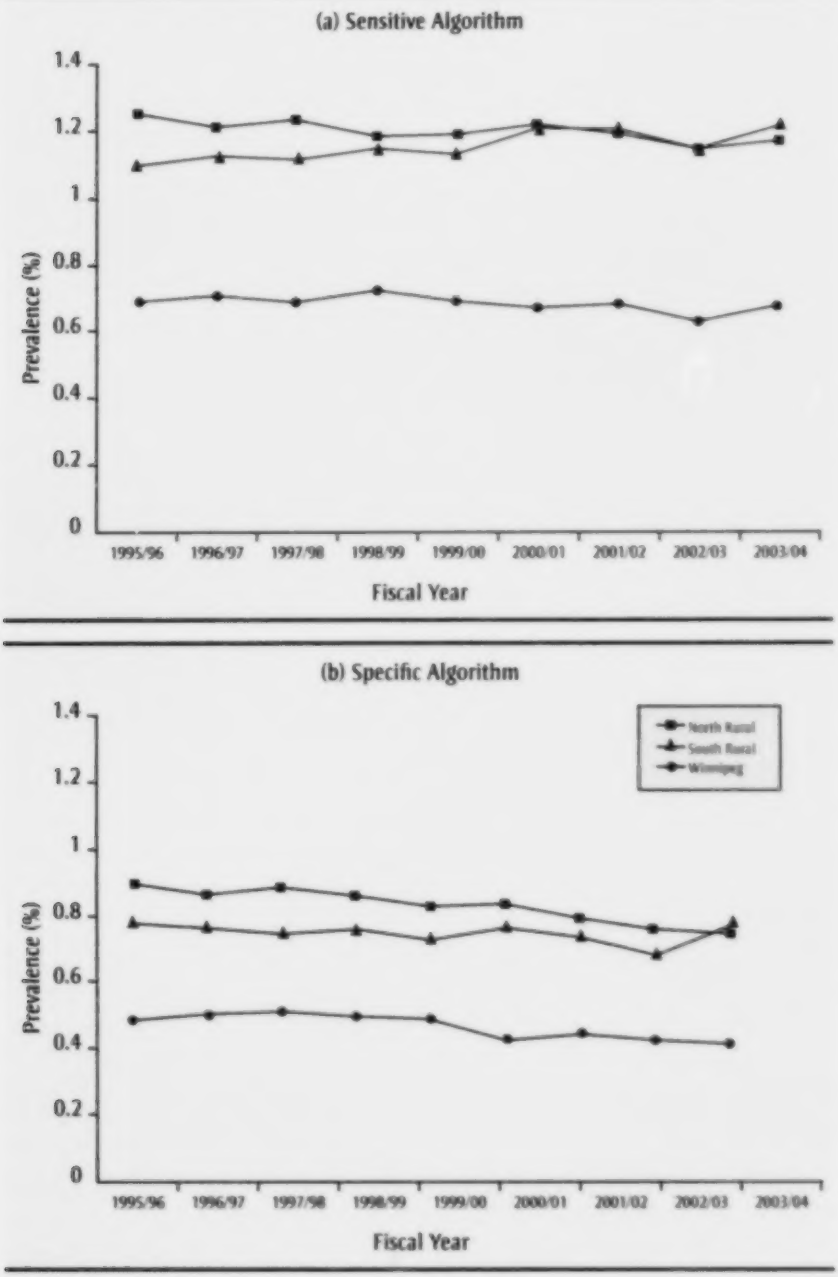
The authors are indebted to Manitoba Health & Healthy Living for the provision of data under project #2004/05-01. This research was supported, in part, by a CIHR New Investigator Award to the second author. The results and conclusions are those of the authors, and no official endorsement by Manitoba Health & Healthy Living is intended or should be inferred. The authors have no competing interests to declare.

FIGURE 1
Trends in crude prevalence of stroke by age group for (a) the sensitive algorithm and (b) the specific algorithm,[a] 1995/96 to 2003/04



[a] The specific algorithm was based on the following ICD-9-CM codes: 430, 431, 434, 435 and 436

FIGURE 2
Trends in crude prevalence of stroke by region of residence for (a) the sensitive algorithm and (b) the specific algorithm,[a] 1995/96 to 2003/04



[a] The specific algorithm was based on the following ICD-9-CM codes: 430, 431, 434, 435 and 436

References

1. Statistics Canada. Selected Leading Causes of Death, By Sex. Ottawa: Statistics Canada, 1997.
2. Verbrugge L, Lepkowski JM, Imanaka Y. Comorbidity and its impact on disability. Milbank Q. 1989;67:450-484.
3. Dobkin B. The Clinical Science of Neurologic Rehabilitation. Second ed. New York: Oxford, 2003:375-376.
4. Wolf P. Epidemiology of stroke. In. Mohr J, Choi DW, Grotta JC, Weir B, Wolf PA, eds. Stroke Pathophysiology, Diagnosis, and Management. Philadelphia: Churchill Livingstone, 2004:13-34.
5. Roos L, Walld R, Uhanova J, Bond R. Physician visits, hospitalizations, and socioeconomic status: Ambulatory care sensitive conditions in a Canadian setting. Health Research and Educational Trust. 2005;10:1167-1185.
6. Kokotailo R, Hill MD. Coding of stroke and stroke risk factors using International Classification of Disease, Revision 9 and 10. Stroke. 2005;36:1776-1781.
7. Lix L, Yogendran M, Burchill C, et al. Defining and Validating Chronic Disease: An Administrative Data Approach. Winnipeg: Manitoba Center for Health Policy, 2006.
8. Yiannakoulias N, Svenson LW, Hill MD, et al. Regional comparison of inpatient and outpatient patterns of cerebrovascular disease diagnosis in the province of Alberta. Chronic Diseases in Canada 2003;24:9-16.
9. Ostbye T, Levy AR, Mayo NE. Hospitalization and case fatality rates for subarachnoid hemorrhage in Canada from 1982 through 1991. Stroke. 1997;28:793-798.
10. Mayo N, Chockalingam A, Reeder BA, et al. Surveillance for stroke in Canada. Health Reports. 1994;6:62-72.
11. Lappala J, Virtamo J, Heinonen OP. Validation of stroke diagnosis in the National Hospital Discharge Register and the Register of Causes of Death in Finland. Euro J Epi. 1999;15:155-160.

12. Benesch C, Witter DM, Wilder MA, et al. Inaccuracy of the International Classification of Diseases (ICD-9-CM) in identifying the diagnosis of ischemic cerebrovascular disease. Neurology. 1997;49:660-664.

13. Tirschwell D, Longstreth WT. Validating administrative data in stroke research. Stroke. 2002;33:2465-2470.

14. Rhys Willams G, Jiang JG, Matchar DB, et al. Incidence and occurrence of total (first-ever and recurrent) stroke. Stroke. 1999;30:2423-2528.

15. The Publication Committee for the Trial of ORG 10172 in Acute Stroke Treatment (TOAST) Investigators. Low molecular weight heparinoid, ORG 1072 (danaparoid) and outcome after acute stroke. JAMA. 1998;279:1265.

16. Adams H, Bendixen BH, Kapele LJ, et al. Classification of subtype of acute ischemic stroke: Definitions for use in a multicenter clinical trial. Stroke. 1993;24:35-41.

17. Kolominisky-Rabas P, Weber M, Gefeller O, et al. Epidemiology of ischemic stroke subtypes according to TOAST criteria, Incidence, recurrence, and long-term survival in ischemic stroke subtypes: A population-based study. Stroke. 2001;32:2735-2740.

18. Stroup D, Berlin JA, Morton SC, et al. Meta-analysis of observational studies in epidemiology - A proposal for reporting. JAMA. 2000;283:2008-2012.

19. Friedman L, Furberg CD, DeMets DL. Fundamentals of Clinical Trials. 3rd ed. New York: Springer, 1998:313-317.

20. SAS Institute Inc. SAS/STAT User's Guide, version 9.1. Cary, NC: SAS Institute Inc., 2004.

21. Roos N, Mustard CA. Variation in health and health care use by socioeconomic status in Winnipeg, Canada: Does the system work well? Yes and No. Milbank Q. 1997;75:89-111.

22. Robinson R, Young KT, Roos L, et al. Estimating the burden of disease: Comparing administrative data and self-reports. Med Care. 1997;35:932-947.

23. Statistics Canada. Provincial and Territorial Profiles, Manitoba. Ottawa, ON: Statistics Canada, 2001.

24. World Health Organization. WHO Collaborating Centre for Drug Statistics Methodology: ATC Classification Index with DDDs and Guidelines for ATC Classification and DDD Assignment. Oslo, Norway: Norwegian Institute of Public Health, 2006.

25. McCulloch CE, Searle SR. Generalized, Linear, and Mixed Models. New York: Wiley, 2001.

26. Fitzmaurice GM, Laird NM, Ware JH. Applied Longitudinal Analysis. Hoboken, NJ: Wiley, 2004.

27. Engelter S, Reichart M, Sekoranja L, et al. Thrombolysis in stroke patients aged 80 years and older: Swiss survey of IV thrombolysis. Neurology. 2005;65:1795-1798.

28. Hemphill J, Lyden P. Stroke thrombolysis in the elderly: Risk or benefit. Neurology. 2005;65:1690-1691.

29. Ellekjaer H, Holmein J, Oystein K, et al. Identification of incident stroke in Norway hospital discharge data compared with a population-based stroke register. Stroke. 1999;30:56-60.

30. Reker DM, Hamilton BB, Duncan PW, et al. Stroke: Who's counting what? J Rehabil Res Devel. 2001;38:281-289.

31. Leibson C, Naessens JM, Brown RD, et al. Accuracy of hospital discharge abstracts for identifying stroke. Stroke. 1994;25:2348-2355.

32. Madans J, Reubens C, Rothwell S, et al. Differences in morbidity measures and risk factor identification using multiple data sources: The case of stroke. J Epidemiol Biostat. 1999;4:37-43.

33. Rector T, Wickstrom SL, Shah M, et al. Specificity and sensitivity of claims-based algorithms for identifying members of Medicare plus Choice health plans that have chronic medical conditions. Health Serv Resear. 2004;39:1839-1861.

Population-based data sources for chronic disease surveillance

LM Lix, PhD (1); MS Yogendran, MSc (2); SY Shaw, MA (3); C Burchill, MSc (2); C Metge, PhD (2,4); R Bond, MA (2)

Abstract

This study estimated agreement between population-based administrative and survey data for ascertaining cases of arthritis, asthma, diabetes, heart disease, hypertension and stroke. Chronic disease case definitions that varied by data source, number of years and number of diagnosis or prescription drug codes were constructed from Manitoba's administrative data. These data were linked to the Canadian Community Health Survey. Agreement between the two data sources, estimated by the κ coefficient, was calculated for each case definition, and differences were tested. Socio-demographic and comorbidity variables associated with agreement were tested using weighted logistic regression. Agreement was strongest for diabetes and hypertension and lowest for arthritis. The case definition elements that contributed to the highest agreement between the two population-based data sources varied across the chronic diseases. Low agreement between administrative and survey data is likely to occur for conditions that are difficult to diagnose, but will be mediated by individual socio-demographic and health status characteristics. Construction of a chronic disease case definition from administrative data should be accompanied by a justification for the choice of each of its elements.

Key words: *chronic disease, case ascertainment, record linkage, population health, surveillance*

Introduction

Population-based data about chronic disease prevalence are essential to describe the burden of disease and to plan and evaluate disease prevention, treatment and management strategies.[1] Administrative databases and self-report responses from health surveys are two key sources of population-based data to estimate chronic disease prevalence.[2-5] Both sources have limitations – the former because of concerns about the accuracy of diagnostic information, and the latter because of concerns about the validity of self-reports of disease diagnosis.[2,6-8] The congruence between the two data sources has been investigated in a few studies using subject-specific record-linkage techniques.[2,9,10] Record linkage also allows for investigation of the individual characteristics that modify agreement between the two data sources.

Systematic investigations of the effect that the choice of an administrative case definition has on agreement between the two population-based data sources are largely absent from the literature. Chronic disease case definitions are constructed by selecting specific combinations of the following administrative data elements: source of data, diagnosis or treatment codes, number of years of data and number of contacts in administrative records with the selected code(s).[9-11] There is no consensus about the optimal case definition, and the choice of case definitions is often based on the availability of data in one's jurisdiction.

This study investigates multiple definitions for ascertaining cases of arthritis, asthma, diabetes, heart disease, hypertension and stroke from administrative data and compares them with self-reports of chronic disease from population-based survey data. The specific objectives are to: 1) test the agreement between administrative and survey data while the elements of a chronic disease case definition are systematically manipulated; and 2) examine individual demographic, geographic, socioeconomic and health status characteristics that may affect agreement between these two data sources.

Methods

The study was conducted using population-based data from Manitoba, a centrally located province in Canada with a universal health care system. The Research Data Repository housed at the Manitoba Centre for Health Policy contains administrative records provided by the provincial health ministry under the Manitoba Health Services Insurance Plan (MHSIP). The Repository also houses population-based survey data from the national Canadian Community Health Survey (CCHS), and the two sources can be directly linked via a unique, anonymized personal health identification number (PHIN).

Hospital, physician and prescription drug databases were selected to construct the case definitions. These administrative databases have been used in other studies to ascertain chronic disease cases.[6,7,10,12] A hospital abstract is completed when a patient is discharged from an acute care facility. Each record includes up to 16 diagnosis codes from the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). All 16 codes were searched to identify disease cases in this study. Physician claims are submitted to the provincial ministry of health by all physicians who are paid on a fee-for-service basis. These claims capture

Author References

1 School of Public Health, University of Saskatchewan, Saskatoon, SK
2 Manitoba Centre for Health Policy, University of Manitoba, Winnipeg, MB
3 Department of Community Health Sciences, University of Manitoba, Winnipeg, MB
4 Faculty of Pharmacy, University of Manitoba, Winnipeg, MB
Correspondence: Lisa M. Lix, School of Public Health, University of Saskatchewan, Health Sciences Building, 107 Wiggins Road, Saskatoon SK S7N 5E5, Tel: 306-966-1617, Email: lisa.lix@usask.ca

all outpatient services, including those for hospital emergency and outpatient departments, and for residents of long-term care facilities. While some physicians are salaried (approximately 7% of family physicians in Manitoba[13]), approximately 90% of these physicians also submit parallel billing claims for administrative purposes. Accordingly, the billing claims database captures almost all contacts with physicians in Manitoba. Physician billing claims contain a single ICD-9-CM code. Outpatient prescription drug records are captured in the Drug Programs Information Network (DPIN), a centralized, electronic, point-of-sale database connecting all retail pharmacies in Manitoba. DPIN collects a variety of information for each dispensation, including the date, drug name and drug identification number (DIN). DINs are linked to Anatomic Therapeutic Chemical (ATC) codes developed by the World Health Organization; these codes classify prescription drugs into groups at each of five levels according to the organ or system on which they act and/or their therapeutic and chemical characteristics.[14] DPIN data have been deemed to be accurate both for capture of drug dispensations as well as the prescription details.[15] The prescription drug database does not contain information about any medications that are obtained without a prescription, including over-the-counter medications, complimentary medication samples distributed directly from physicians to patients, or medications dispensed to hospitalized inpatients or residents of long-term care facilities.

The CCHS provides cross-sectional estimates of health status, health determinants, and health system use for residents of 136 health regions in Canada, including 11 Manitoba regions.[16] The survey uses a multi-stage stratified clustered design. It represents approximately 98% of the Canadian population aged 12 years or older. In cycle 1.1, collected between September 2000 and November 2001, there were 8120 Manitoba respondents.

Anonymized linkage between administrative and survey data was conducted for those survey respondents who provided their consent (n = 7560; 93.1%). After removing invalid or missing PHINs, direct linkage between administrative and survey data was achieved for 6812 respondents (i.e. 83.9% of respondents). A cohort of survey respondents with at least five years of continuous coverage under the MHSIP prior to their interview date was created (n = 6422). The study excluded respondents with less than five years of coverage because preliminary analyses revealed that discontinuous health insurance coverage was associated with lower agreement between survey and administrative data. The administrative data were from fiscal years 1997/98 to 2001/02.

The survey interview schedule included the following directions: "*Now I'd like to ask about certain chronic health conditions which you may have. We are interested in 'long-term conditions' that have lasted or are expected to last six months or more and that have been diagnosed by a health professional*". Table 1 lists the relevant questions.

A total of 152 case definitions were investigated (the complete list is available from the corresponding author upon request), and were developed using previous research as a guide.[5,9-11,17-27] Some definitions were based only on a single administrative data source, while others were based on multiple data sources. The case definitions varied by the number of years of administrative data (one, two, three and five), in accordance with previous research.[9] Some case definitions required only a single contact in administrative data, while other definitions required more than one contact. The constants in the construction of the case definitions were the diagnosis (i.e. ICD-9-CM) and prescription drug (i.e. ATC) codes (Table 1); these were identified from a comprehensive literature review.[28]

Cohen's kappa coefficient (κ) was used to quantify agreement between the two data sources; 95% confidence intervals (95% CIs) were also computed. The estimates and CIs were computed using the sample weights from the survey data. Kappa is a commonly adopted measure because it corrects the agreement between two sources by taking account of the proportion of agreement expected by chance. The magnitude of agreement was assessed as follows:[29] poor agreement: $\hat{\kappa} < 0.20$; fair agreement: $0.20 \leq \hat{\kappa} < 0.40$; moderate agreement: $0.40 \leq \hat{\kappa} < 0.60$; good agreement: $0.60 \leq \hat{\kappa} < 0.80$; and very good agreement: $\hat{\kappa} \geq 0.80$.

Differences between selected κ coefficients (i.e. H_0: $\kappa_1 = \kappa_2$) were tested using a goodness-of-fit statistic,[30] which approximately follows an χ^2 distribution. The tests were conducted for case definitions based on different sources or years of data or number of contacts. All comparisons were identified *a priori*, and the per-comparison error rate was set at $\alpha = 0.05$.

For each chronic disease, a single case definition with the highest estimated agreement was selected to further investigate the respondent characteristics associated with agreement between population-based administrative and survey data. Weighted logistic

TABLE 1
Survey questions, ICD-9-CM diagnosis codes, and ATC prescription drug codes for chronic disease case ascertainment

Disease	Survey Questions	ICD-9-CM Codes	ATC Codes[b]
Arthritis	Do you have arthritis or rheumatism, excluding fibromyalgia?	714, 715, 446, 710, 720, 274, 711-713, 716, 717, 718 719, 721, 725-729, 739	A07, J01, L01, L04, M01, P01, N02, R05, H02
Asthma	Do you have asthma?	493	R03, R06
Diabetes	Do you have diabetes?	250	A10
Heart Disease	Do you have heart disease? [a]	410-414	C01, C07, C08, C09
Hypertension	Do you have high blood pressure?	401	C02, C03, C07, C08, C09
Stroke	Do you suffer from the effects of a stroke?	430-438	B01

[a] Individuals with congestive heart failure were excluded from the "heart disease" category

[b] Not all drugs in each ATC category were selected. For a comprehensive list of prescription drug inclusions and exclusions please refer to the following URL: http://mchp-appserv.cpe.umanitoba.ca/reference/chronic.disease.pdf

regression analyses modeled agreement as a function of socio-demographic and disease variables, including age group (12 to 18, 19 to 49, 50 to 64, 65 to 74, 75 + [reference]), sex (male, female [reference]), region of residence (rural, urban [reference]), income adequacy quintile (highest income group was the reference) and presence/absence of comorbid conditions (presence was the reference).[31,32] CCHS methodologists developed income adequacy quintiles using self-reported total household income and number of persons living in the household. The following comorbid conditions were selected: allergies, emphysema or chronic obstructive pulmonary disease for asthma; heart disease or hypertension for diabetes; diabetes or hypertension for heart disease; diabetes or heart disease for hypertension; and heart disease or diabetes for stroke. Odds ratios (ORs) and 95% CIs are reported. All analyses were conducted using SAS software, version 9.1.

Ethics approval was obtained from the University of Manitoba Health Research Ethics Board. Approval for data access was from the Manitoba Health Information Privacy Committee.

Results

Only adult (19 years and older) respondents (n = 5589; 87.0%) were the subject of the investigation on agreement between population-based administrative and health survey data for diabetes, heart disease, hypertension, arthritis and stroke, while both adult and youth respondents were selected for the asthma analyses. Almost half (46.1%) of individuals in the adult study cohort were 50 years of age or older. Slightly less than half of the entire cohort (45.3%) was male, and almost one-quarter of the individuals (23.1%) were urban residents. The CCHS oversampled rural residents so that estimates could be generated for individual health regions.

The number and percent of the study cohort that reported each of the chronic diseases is given in Table 2. Weighted estimates of chronic disease prevalence were computed from the survey data (see Table 2), and ranged from 1.5% for stroke to 18.6% for arthritis. These provincial estimates are consistent with estimates reported in self-report survey data from other provincial and national studies.[33-35]

Figure 1 depicts the variation in estimates of the κ coefficient for all investigated case definitions. For arthritis, κ ranged from 0.15 to 0.34, indicating poor to fair agreement. For asthma, the estimates ranged from 0.27 to 0.59, which represents fair to moderate agreement. Agreement for diabetes was good or very good, and ranged from 0.65 to 0.83. For heart disease, κ ranged from 0.29 to 0.55, indicating fair to moderate agreement. For hypertension, the range was from 0.53 to 0.72, indicating moderate to good agreement. Finally for stroke, κ ranged from 0.27 to 0.58, which represents fair to moderate agreement.

Table 3 reports κ for selected case definitions along with the results of the inferential analyses. Tests of the differences in agreement between case definitions that required only a single contact in physician claims, and case definitions that required two or more contacts in physician claims, were conducted. When one year of administrative data was used, significantly lower values of κ were observed for the latter case definition than for the former for all chronic diseases. However, when two or more years of administrative data were used to construct the case definition, the pattern of differences in agreement varied. For arthritis and diabetes, estimates of agreement were always significantly higher for the two-contact case definition than the one-contact case definition,

FIGURE 1
Weighted κ for chronic disease case definitions from administrative data

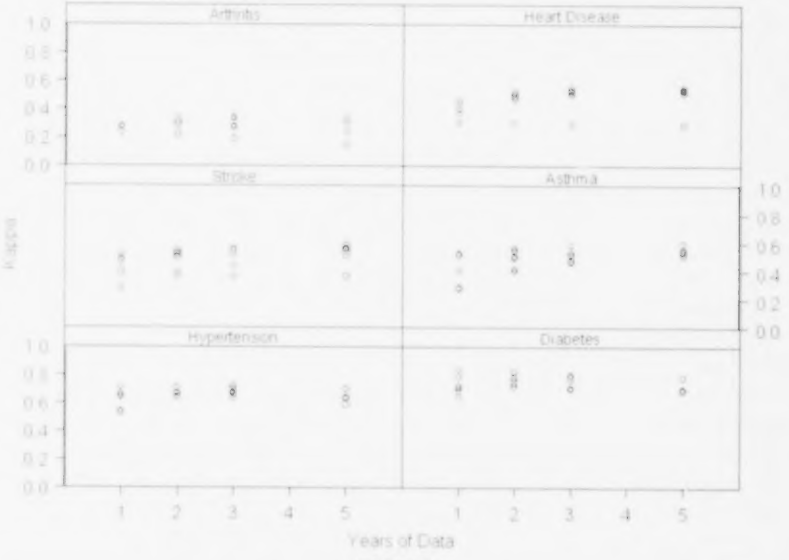


TABLE 2
Frequency (percent) of study cohort with self-reported chronic disease and prevalence estimates from the Canadian Community Health Survey cycle 1.1

Disease	Adult Cohort (n = 5589)	Youth Cohort (n = 833)	Prevalence (%) (95% CI)[a]
Arthritis	1344 (24.0)	–	18.6 (17.4 to 19.8)
Asthma	418 (7.5)	111 (13.5)	8.6 (7.6 to 9.6)
Diabetes	337 (6.0)	–	4.5 (3.9 to 5.2)
Heart Disease	371 (6.6)	–	5.1 (4.4 to 5.7)
Hypertension	1033 (18.5)	–	15.3 (14.2 to 16.5)
Stroke	108 (1.9)	–	1.5 (1.1 to 1.8)

[a] Prevalence estimates were calculated for the population 19 years and older, except for asthma prevalence, which was calculated for the population 12 years and older. Prevalence estimates are based on survey weights, and confidence intervals were calculated using bootstrap variance estimation methods

TABLE 3

Weighted κ (95% CI) for selected chronic disease case definitions from administrative data[a,b,c,d]

Source and Years of Data	Arthritis	Asthma	Diabetes	Heart Disease	Hypertension	Stroke
Physician (P)[a]	**1 P**	**1 P**	**1 P**	**1 P**	**1 P**	**1P**
1	0.27 (0.26,0.27)	0.40 (0.35,0.44)	0.69 (0.68,0.69)	0.44 (0.39,0.49)	0.64 (0.64,0.64)	0.47 (0.47,0.48)
2	**0.29** (0.28,0.29)	0.49 (0.45,0.54)	**0.72** (0.72,0.73)	0.51 (0.46,0.55)	**0.66** (0.66,0.67)	**0.54** (0.53,0.54)
3	0.27 (0.27,0.28)	0.53 (0.49,0.57)	0.70 (0.69,0.70)	**0.52** (0.48,0.56)	**0.66** (0.66,0.67)	0.51 (0.50,0.52)
5	0.24 (0.24,0.24)	**0.55** (0.51,0.59)	0.69 (0.69,0.69)	**0.52** (0.48,0.57)	0.63 (0.63,0.64)	**0.54** (0.54,0.55)
	2 + P	**2 + P**	**2 + P**	**2 + P**	**2 + P**	**2 + P**
1	0.23 (0.23,0.23)*	0.27 (0.23,0.32)*	0.65 (0.65,0.66)*	0.37 (0.31,0.42)*	0.53 (0.52,0.53)*	0.41 (0.40,0.42)*
2	0.31 (0.30,0.31)*	0.40 (0.35,0.44)*	0.76 (0.75,0.76)*	0.47 (0.42,0.52)*	0.64 (0.64,0.65)*	0.49 (0.48,0.50)*
3	**0.34** (0.33,0.34)*	0.46 (0.42,0.51)*	**0.78** (0.78,0.79)*	0.50 (0.46,0.55)*	0.68 (0.68,0.68)*	0.55 (0.54,0.56)*
5	0.33 (0.33,0.34)*	**0.54** (0.50,0.58)	**0.78** (0.78,0.79)*	**0.54** (0.49,0.58)*	**0.70** (0.70,0.70)*	**0.58** (0.57,0.59)*
Hospital (H), Physician(P)[b]	**1 + H or 2 + P**	**1 + H or 1 + P**	**1 + H or 1 + P**	**1 + H or 2 + P**	**1 + H or 2 + P**	**1 + H or 2 + P**
1	0.23 (0.23,0.24)	0.40 (0.36,0.45)	0.72 (0.72,0.73)†	0.40 (0.34,0.45)†	0.54 (0.54,0.54)†	0.48 (0.47,0.48)†
2	0.31 (0.31,0.31)	0.50 (0.46,0.54)	0.74 (0.73,0.74)†	0.49 (0.44,0.54)†	0.66 (0.65,0.66)†	0.52 (0.51,0.53)†
3	**0.34** (0.34,0.34)	0.53 (0.50,0.57)	**0.70** (0.70,0.71)†	0.53 (0.49,0.58)†	0.70 (0.69,0.70)†	0.55 (0.54,0.55)
5	0.33 (0.33,0.34)	**0.55** (0.51,0.59)	**0.70** (0.69,0.70)†	**0.55** (0.51,0.59)†	**0.71** (0.71,0.71)†	**0.56** (0.55,0.57)†
Hospital (H), Physician(P), Prescription(Rx)[c]	**1 + H or 2 + P or (1 + P & 2 + Rx)**	**1 + H or 1 + P or 1 + Rx**	**1 + H or 1 + P or 1 + Rx**	**1 + H or 2 + P or (1 + P & 2 + Rx)**	**1 + H or 2 + P or (1 + P & 2 + Rx)**	**1 + H or 2 + P or (1 + P & 2 + Rx)**
1	0.28 (0.28,0.28)‡	0.52 (0.48,0.56)‡	**0.79** (0.79,0.80)‡	0.46 (0.41,0.51)‡	0.66 (0.66,0.67)‡	0.51 (0.50,0.52)‡
2	**0.33** (0.33,0.33)‡	**0.54** (0.50,0.57)‡	0.76 (0.76,0.77)‡	0.52 (0.48,0.57)‡	0.71 (0.71,0.71)‡	0.51 (0.51,0.52)
3	**0.33** (0.33,0.34)‡	0.51 (0.48,0.55)	0.71 (0.71,0.72)‡	**0.55** (0.50,0.59)‡	**0.72** (0.71,0.72)‡	0.54 (0.53,0.55)
5	0.31 (0.31,0.31)‡	0.48 (0.45,0.51)‡	0.69 (0.69,0.70)	**0.55** (0.51,0.60)	0.70 (0.70,0.71)‡	**0.55** (0.54,0.55)‡

[a] Numeric values in bold typeface represent the highest kappa value(s) in each set of case definitions

[b] Star (*) denotes a statistically significant difference between an algorithm based on one contact in physician claims and an algorithm based on two or more contacts in physician claims ($p < 0.05$); all comparisons are based on the same number of years of data

[c] Dagger (†) denotes a statistically significant difference between an algorithm based on physician data (either one contact or two contacts) and an algorithm based on hospital and physician data ($p < 0.05$); all comparisons are based on the same number of years of data

[d] Double Dagger (‡) denotes a statistically significant difference between an algorithm based on hospital and physician data and an algorithm based on hospital, physician and prescription drug data ($p < 0.05$); all comparisons are based on the same number of years of data

while for asthma the reverse was true. For heart disease, hypertension and stroke, agreement could be significantly higher or lower depending on the number of years of data used to construct the case definition.

Tests of the differences between case definitions based on diagnoses in physician records (either one or two contacts, depending on the disease) and case definitions based on both hospital and physician records were conducted for single and multiple years of administrative data (Table 3). When hospital data were included, statistically significant improvements in agreement were observed for all diseases with the exception of arthritis and asthma. For the other conditions, agreement almost always improved regardless of whether single or multiple years of data were used to construct the case definition.

Finally, Table 3 reports tests of the differences between case definitions based on diagnoses in hospital and physician records and case definitions based on both diagnosis and prescription drug codes. For all chronic diseases, the combination of diagnostic and prescription drug data resulted in a statistically significant improvement in agreement when one year of data were used to construct the case definitions. This was not consistently the case when two or more years of data were used to construct the case definition. In fact when five years of data were used, agreement either did not improve or got worse for all diseases.

The ORs for the weighted logistic regression analyses are reported in Table 4. Age was statistically significant in all models ($p < 0.0001$). The odds of agreement between administrative and survey data were almost always higher for individuals in younger than in older age groups. Sex was also associated with agreement for all chronic diseases, although the magnitude and direction of the effect varied. It was strongest for diabetes and stroke. For arthritis, asthma, diabetes and stroke, the odds of agreement were significantly higher for males than females, while the converse was true for heart disease, hypertension and stroke.

Region of residence was statistically significant for all chronic diseases ($p < 0.0001$) with the exception of asthma. The strength of the association was weakest for arthritis and hypertension. The odds of agreement were higher for rural than urban residents for arthritis, diabetes, heart disease and stroke, while the converse was true for hypertension.

TABLE 4

Odds Ratios* (95% CIs) for predictors of agreement between administrative and survey data for chronic diseases

	Arthritis	Asthma	Diabetes[a,b]	Heart Disease[a,b]	Hypertension	Stroke[a]
Age						
12 to 18 years	–	1.38 (1.33 to 1.43)	–	–	–	–
19 to 49 years	3.67 (3.62 to 3.77)	2.17 (2.11 to 2.24)	–	–	6.00 (5.83 to 6.17)	–
50 to 64 years	1.57 (1.53 to 1.60)	1.86 (1.79 to 1.92)	2.34 (2.28 to 3.46)	8.46 (8.21 to 8.72)	2.42 (2.35 to 2.48)	13.47 (12.75 to 14.23)
65 to 74 years	1.39 (1.35 to 1.42)	1.85 (1.78 to 1.93)	0.85 (0.81 to 0.89)	1.77 (1.71 to 1.82)	1.93 (1.88 to 1.99)	1.90 (1.81 to 1.99)
75+ years	Ref	Ref	Ref	Ref	Ref	Ref
Sex						
Males	1.09 (1.08 to1.11)	1.05 (1.03 to 1.07)	1.40 (1.35 to 1.45)	0.83 (0.81 to 0.85)	0.81 (0.79 to 0.82)	0.44 (0.42 to 0.46)
Females	Ref	Ref	Ref	Ref	Ref	Ref
Residence						
Rural	1.06 (1.04 to 1.07)	1.01 (0.99 to 1.02)	1.18 (1.14 to 1.22)	1.31 (1.28 to 1.34)	0.89 (0.88 to 0.91)	1.28 (1.23 to 1.33)
Urban	Ref	Ref	Ref	Ref	Ref	Ref
Income quintile						
Lowest	0.66 (0.68 to 0.71)	0.33 (0.31 to 0.34)	–	–	0.84 (0.80 to 0.89)	0.07 (0.06 to 0.09)
Low-middle	1.06 (1.03 to 1.09)	0.71 (0.68 to 0.74)	1.07 (1.00 to 1.13)	0.87 (0.83 to 0.91)	1.06 (1.02 to 1.11)	0.10 (0.09 to 0.13)
Middle	0.98 (0.96 to 1.00)	0.59 (0.57 to 0.60)	1.04 (0.99 to 1.09)	0.66 (0.63 to 0.68)	1.10 (1.07 to 1.13)	0.19 (0.17 to 0.21)
Upper-middle	0.91 (0.90 to 0.93)	0.66 (0.64 to 0.68)	1.32 (1.26 to 1.38)	0.78 (0.76 to 0.82)	1.15 (1.12 to 1.18)	0.18 (0.16 to 0.20)
Highest	Ref	Ref	Ref	Ref	Ref	Ref
Comorbid conditions						
Absent	–	1.90 (1.82 to 1.94)	3.09 (2.97 to 3.21)	2.73 (2.66 to 2.80)	2.96 (2.89 to 3.03)	2.97 (2.84 to 3.10)
Present	Ref	Ref	Ref	Ref	Ref	Ref

* Statistically significant at $\alpha = .05$

[a] The 19 to 49 and 50 to 64 years age groups were combined because of small cell sizes for the former category

[b] Low-middle and middle income quintile categories were combined because of small cell sizes for the former category

Income quintile was also associated with agreement between administrative and survey data ($p < 0.0001$). The odds of agreement were generally lower for individuals in poorer income quintiles than for those in wealthier quintiles, except for diabetes and hypertension, where the converse was true.

Finally, the comorbidity variable was statistically significant in all models ($p < 0.0001$); the odds of agreement were consistently higher when a comorbid condition was absent than when it was present. The association between comorbidity and agreement was of a similar magnitude for all chronic diseases except asthma, for which the relationship was weakest.

Conclusions

This record-linkage study compared chronic disease case ascertainment in population-based administrative and self-report survey data while the elements of the case definition in administrative data were systematically manipulated. It also investigated the individual characteristics that moderate agreement between these two data sources. The results show that regardless of the case definition adopted, agreement between these two data sources was highest for diabetes and hypertension, and lowest for arthritis. These findings are consistent with previous research that has compared administrative case definitions and self-reported chronic disease in population-based and clinical samples.[2,9,10,19,22,31] Okura et al. theorize that although diabetes and hypertension are not usually characterized by distinct and dramatic clinical presentations, they are "...chronic and require ongoing repeated engagement with the medical care system."[31(p. 1101)] which increases their likelihood of identification in administrative data. For arthritis, the selection of non-specific diagnostic codes by practitioners, potentially inaccurate diagnoses by non-specialized practitioners and the low probability that this condition will contribute to a hospital stay may all be factors contributing to the lack of concordance between the two data sources.[36] As well, some diseases may not be accurately captured via self-report. For example, Kriegsman et al.[37] argues that because of the non life-threatening nature of arthritis, it may be overreported in surveys, but underreported in administrative data, contributing to the lack of agreement between the two sources. Questionnaire wording is also an important factor in assessing the accuracy of survey data.

Agreement between administrative and survey data varied significantly as a function of the elements of type of data, number of years of data and number of contacts,[9,10] although the magnitude of the differences in κ estimates among the case definitions was sometimes quite small. Multiple types and/or years of data usually

resulted in improved agreement between administrative and survey data, but this observation cannot be generalized across all of the investigated diseases. Improvements in agreement were not always evident when three or five years of data were used to construct the case definition. Using prescription drug data in addition to hospital and physician data to ascertain disease cases had mixed effects on agreement. While case ascertainment for asthma benefited from the use of both diagnostic and prescription drug information when the definition was based on one or two years of administrative data, improvements in agreement were less substantial for diabetes. For hypertension, there was also some improvement in agreement associated with using both diagnosis and prescription drug data for case ascertainment, but not for other diseases. A specific set of prescription drugs are used to treat asthma and diabetes; for other chronic diseases such as hypertension or arthritis, the drugs prescribed for an individual may be used to treat more than one chronic disease, and therefore may not be helpful for identifying cases.

The moderating effect of demographic, geographic, socioeconomic and health status variables on agreement between survey and administrative data has been observed in other studies.[38-40] Simpson et al.[39] found, however, that the absence of comorbid conditions was associated with both increased and decreased agreement, depending on the disease, while this study found that agreement consistently improved when comorbid conditions were absent.

One potential limitation of this research is that a fixed set of diagnosis and prescription drug codes was selected. Some studies have compared case ascertainment results for different sets of diagnosis codes. For example, studies of stroke case ascertainment have sometimes excluded non-specific diagnostic codes such as 437, which represents stroke of undetermined causes.[24,41] The exclusion of non-specific diagnostic codes might improve estimates of agreement between administrative and survey data. However, when our analyses for stroke were repeated and restricted to a narrow set of diagnostic codes (i.e. 430, 431, 434, 345, 436), estimates of the κ coefficient were never higher than the estimates obtained using the full set of codes. This study was conducted using administrative data coded with ICD-9-CM. In the 2004/05 fiscal year, a change was made to ICD-10-CA in Manitoba's hospital databases. Future research will investigate the effect of this change on chronic disease case ascertainment. Agreement between the two data sources may have been moderated by the survey interview date, a factor that was not considered in this study. Finally, this study was limited to a set of conditions for which there were sufficient data available to investigate agreement; absent from this list are other forms of chronic respiratory disease, such as chronic obstructive pulmonary disease, musculoskeletal conditions such as osteoporosis, and gastro-intestinal conditions such as inflammatory bowel disease.

The strengths of this study are that it assesses agreement using three administrative databases that are available in many jurisdictions. It focuses on the incremental benefits of using different data elements in constructing a case definition, and it systematically examines the effect of using both diagnosis and prescription drug information. Finally, it uses record-linkage techniques for individuals to investigate the variables associated with agreement between two population-based data sources. Researchers who construct case definitions from administrative data should be cognizant of the effect that the choice of administrative data elements has on case ascertainment. The selection of a case definition should be justified by describing the potential effects associated with manipulating each data element.

The results of this study suggest a number of further opportunities for research on constructing case definitions from administrative data. The first is to stratify the population on important socio-demographic and/or health status variables and then specify and test case definitions for each of these strata. For example, an algorithm based on a single contact in physician claims in one year of data might result in high agreement for youth with asthma, whereas an algorithm based on two or more contacts in physician claims might result in higher agreement for older adults with asthma. Researchers might also consider a model-based approach that uses classification techniques to construct a case definition.[42-43] A model-based approach can accommodate a large set of variables (i.e. data features), including comorbid conditions, contacts with specialists, socio-demographic variables and indicators of disease diagnosis and treatment, and test the relative contribution of these variables to improving case ascertainment. Finally, additional validation studies that use data repositories in other provinces or that adopt a "gold standard" data source, such as laboratory test results or clinical data about disease diagnosis, will aid in understanding the strengths and limitations of administrative data for monitoring chronic disease. In particular, studies that adopt a gold standard can provide estimates of the sensitivity and specificity of case definitions derived from administrative data. However, because an unbiased gold standard does not exist for some chronic diseases, such as arthritis and irritable bowel disease, further research is also needed about validation techniques in the presence of measurement error.[44-45]

Acknowledgements

This research was supported by funding from Manitoba Health & Healthy Living and a grant from the Canadian Institutes of Health Research (#PPR79240). The authors are indebted to Manitoba Health & Healthy Living for the provision of data under project #2004/05-01. The results and conclusions are those of the authors, and no official endorsement by Manitoba Health & Healthy Living is intended or should be inferred. The authors have no competing interests to declare.

References

1. Thacker SB, Stroup DF, Rothenberg RB, Brownson RC. Public health surveillance for chronic conditions: a scientific basis for decisions. Stat Med. 1995;14:629-641.

2. Cricelli C, Mazzaglia G, Samani F, Marchi M, Sabatini A, Nardi R, Ventriglia G, Caputi AP. Prevalence estimates for chronic diseases in Italy: exploring the differences between

self-report and primary care databases. J Public Health Med. 2003;25:254-257.

3. Powell KE, Diseker RA, Presley RJ, Tolsma D, Harris S, Mertz KJ, Viel K, Conn DL, McClellan W. Administrative data as a tool for arthritis surveillance: estimating prevalence and utilization of services. J Public Health Manag Pract. 2003;9:291-298.

4. Umphrey GJ, Kendall O, MacNeill IB. Assessing the surveillance capability of Canada's national health surveys. Chronic Dis Canada. 2001;22:50-56.

5. Mayo NE, Chockalingam A, Reeder BA, Phillips S. Surveillance for stroke in Canada. Health Rep. 1994;6:62-72.

6. Saydah SH, Geiss LS, Tierney E, Benjamin SM, Engelgau M, Brancati F. Review of the performance of methods to identify diabetes cases among vital statistics, administrative and survey data. AEP. 2004;14:507-516.

7. Maio V, Yuen E, Rabinowitz C, Louis D, Jimbo M, Donatini A, Mall S, Taroni F. Using pharmacy data to identify those with chronic conditions in Emilia Romagna, Italy. J Health Serv Res Policy. 2005;10:232-238.

8. Mahonen M, Salomaa V, Brommels M, Molarius A, Miettinen H, Pyorala K, Tuomilehto J, Arstila M, Kaarsalo E, Ketonen M, Kuulasmaa K, Lehto S, Mustaniemi H, Niemela M, Palomaki P, Torppa J, Vuorenmaa T. The validity of hospital discharge register data on coronary heart disease in Finland. Eur J Epidemiol. 1997;13:403-415.

9. Robinson JR, Young TK, Roos LL, Gelskey DE. Estimating the burden of disease. Comparing administrative data and self-reports. Med Care. 1997;35:932-947.

10. Rector TS, Wickstrom SL, Shah M, Greenlee NT, Rheault P, Rogowski J, Freedman V, Adams J, Escarce JJ. Specificity and sensitivity of claims-based algorithms for identifying members of Medicare plus Choice health plans that have chronic medical conditions. Health Serv Res. 2004;39:1839-1861.

11. Hux JE, Ivis F, Flintoft V, Bica A. Diabetes in Ontario: determination of prevalence and incidence using a validated administrative data algorithm. Diabetes Care. 2002;25:512-516.

12. Virning BA, McBean M. Administrative data for public health surveillance and planning. Annu Rev Public Health. 2001;22:213-230.

13. Watson DE, Katz A, Reid RJ, Bogdanovic B, Roos NP, Heppner P. Family physician workloads and access to care in Winnipeg: 1991 to 2001. CMAJ. 2004;171:339-342.

14. World Health Organization. WHO Collaborating Centre for Drug Statistics Methodology: ATC classification index with DDDs and Guidelines for ATC classification and DDD assignment. Oslo, Norway: Norwegian Institute of Public Health, 2006.

15. Kozyrskyj AL, Mustard CA. Validation of an electronic, population-based prescription database. Ann Pharmacother. 1998;32:1152-57.

16. Statistics Canada. Canadian Community Health Survey (CCHS) - Cycle 1.1. Ottawa: Statistics Canada 2005. URL: http://www.statcan.ca/english/concepts/hs/index.htm.

17. Wilchesky M, Tamblyn RM, Huang A. Validation of diagnostic codes within medical services claims. J Clin Epidemiol. 2004;57:131-141.

18. Kozyrskyj AL, Mustard CA, Becker AB. Identifying children with persistent asthma from health care administrative records. Can Respir J. 2004;11:141-145.

19. Huzel L, Roos LL, Anthonisen NR, Manfreda J. Diagnosing asthma: the fit between survey and administrative database. Can Respir J. 2002;9:407-412.

20. Macy E, Schatz M, Gibbons C, Zeiger R. The prevalence of reversible airflow obstruction and/or methacholine hyperreactivity in random adult asthma patients identified by administrative data. J Asthma. 2005;42:213-220.

21. Morgan CL, Currie CJ, Stott NC, Smithers M, Butler CC, Peters JR. Estimating the prevalence of diagnosed diabetes in a health district of Wales: the importance of adjustment for death and migration. Diabet Med. 2000;17:141-145.

22. Muhajarine N, Mustard C, Roos LL, Young TK, Gelskey DE. Comparison of survey and physician claims data for detecting hypertension. J Clin Epidemiol. 1997;50:711-718.

23. Leibson CL, Maessens JM, Brown RD, Whisnant JP. Accuracy of hospital discharge abstracts for identifying stroke. Stroke. 1994;25:2348-2355.

24. Tirschwell DL, Longstreth WT. Validating administrative data in stroke research. Stroke. 2002;33:2465-2470.

25. Rawson NS, Malcolm E. Validity of the recording of ischaemic heart disease and chronic obstructive pulmonary disease in the Saskatchewan Health care data files. Stat Med. 1995;14:2627-2643.

26. Shah BR, Hux JE, Zinman B. Increasing rates of ischemic heart disease in the native population of Ontario, Canada. Arch Intern Med. 2000;160:1862-1866.

27. Bullano MF, Kamat S, Willey VJ, Barlas S, Watson DJ, Brenneman SK. Agreement between administrative claims and the medical record in identifying persons with a diagnosis of hypertension. Med Care 2006;44:486-490.

28. Lix LM, Yogendran M, Burchill C, McKeen N, Metge C, Moore D, Bond R. Defining and validating chronic diseases: An administrative data approach. University of Manitoba: Manitoba Centre for Health Policy, 2006.

29. Altman DG. Practical Statistics for Medical Research. London: Chapman & Hall, 1991.

30. Donner A, Shoukri MM, Klar N, Bartfay E. Testing the equality of two dependent kappa statistics. Stat Med. 2000;19:373-387.

31. Okura Y, Urban LH, Mahoney DW, Jacobsen SJ, Rodeheffer RJ. Agreement between self-report questionnaires and medical record data was substantial for diabetes, hypertension, myocardial infarction and stroke but not for heart failure. J Clin Epidemiol. 2004;57:1096-1103.

32. Borzecki AM, Wong AT, Hickey EC, Ash AS, Berlowitz DR. Identifying hypertension-related comorbidities from administrative data: what's the optimal approach? Am J Med Qual. 2004;19:201-206.

33. Heart and Stroke Foundation of Canada. The Changing Face of Heart Disease and Stroke in Canada 2000. Ottawa: Health Canada, 2000.

34. Health Canada. Diabetes in Canada. 2nd ed. Ottawa: Health Canada, 2002.

35. Wolff HK, Andreou P, Bata IR, Comeau DG, Gregor RD, Gephart G, MacLean DR, Sketris I. Trends in the prevalence and treatment of hypertension in Halifax county from 1985-1995. CMAJ. 1999;161:699-704.

36. Harrold LR, Yood RA, Andrade SE, Reed JI, Cernieux J, Straus W, Weeks M, Lewis B, Gurwitz JH. Evaluating the predictive value of osteoarthritis diagnoses in an administrative database. Arthritis Rheum. 2000;43:1881-1885.

37. Kriegsman DM, Penninx BW, van Eijk JT, Boeke AJ, Deeg DJ. Self-reports and general practitioner information on the presence of chronic diseases in community dwelling elderly. J Clin Epidemiol. 1996;49:1407-1417.

38. Haapanen N, Miilunpalo S, Pasanen M, Oja P, Vuori I. Agreement between questionnaire data and medical records of chronic diseases in middle-aged and elderly Finnish men and women. Am J Epidemiol. 1997;145:762-769.

39. Simpson CF, Boyd CM, Carlson MC, Griswold ME, Guralnik JM, Fried LP. Agreement between self-report of disease diagnoses and medical record validation in disabled older women: factors that modify agreement. J Am Geriatr Soc. 2004;52:123-127.

40. Verbrugge LM, Lepkowski JM, Imanaka Y. Comorbidity and its impact on disability. Milbank Q. 1989;67:450-484.

41. Benesch C, Witter DM, Wilder AL, Duncan PW, Samsa GP, Matchar DB. Inaccuracy of the International Classification of Disease (ICD-9-CM) in identifying the diagnosis of ischemic cerebrovascular disease. Neurology. 1997;49:660-664.

42. Hirsch S, Shapiro JL, Turega MA, Frank TL, Niven RM, Frank PI. Using a neural network to screen a population for asthma. Ann Epidemiol. 2001;11:369-376.

43. Shanker M, Hu MY, Hung MS. Estimating probabilities of diabetes mellitus using neural networks. SAR QSAR Environ Res. 2000;11:133-147.

44. Ladouceur M, Rahme E, Pineau CA, Joseph L. Robustness of prevalence estimates derived from misclassified data from administrative databases. Biometrics 2007;63(1):272-279.

45. Cole SR, Haitao C, Greenland S. Multiple-imputation for measurement-error correction. Int J Epidemiol. 2006;35:1074-1081.

The Second National Sun Survey: Workshop report

Bronwen Waller, MHSc (1); Erin Pichora, MSc (1); Loraine Marrett, PhD (1,2)

Introduction

Ultraviolet radiation (UVR) from the sun is the major cause of skin cancer. An estimated 77 600 Canadians are diagnosed with skin cancer each year, making it the most common form of cancer.[1] Developing public health programs to decrease its incidence by reducing unnecessary sun exposure requires accurate, up-to-date information about how much time people spend in the sun, their use of sun protection, and their knowledge, attitudes and behaviours concerning tanning, sun exposure and sun protection.

The Second National Sun Survey (NSS2) was conducted in 2006, 10 years after the Canadian National Survey on Sun Exposures and Protective Behaviours, 1996 (NSS1),[2] under the auspices of the National Skin Cancer Prevention Committee of the Canadian Strategy for Cancer Control. The NSS2 was designed to estimate:

- current levels of sun exposure, protective behaviours and use of tanning equipment in adults 16+ by age, sex and region (province or aggregations thereof);
- current levels of sun exposure and protective behaviours in children aged 1-12 for Canada as a whole; and
- levels of knowledge, attitudes and beliefs about sun safety in adults 16+ by age, sex and region.

The NSS2 was also designed to compare levels of sun exposure and protective behaviours in Canadian adults aged 16 years and older by age and sex between the NSS2 and the NSS1.

For the first three objectives, a sample of 7121 Canadian adults (the base sample), was interviewed by telephone, with a questionnaire that encompassed all specified areas of interest. To address the fourth objective, an additional 2115 adults (the comparison sample) were asked a reduced set of questions from the NSS1.

An important objective of the survey is knowledge transfer. Therefore, components such as promoting awareness of the survey and its data, enhancing capacity to analyze the data, and producing reports to meet the needs of a wide range of stakeholders, including public health professionals, health promotion experts, planners, policy-makers and sun safety researchers were included in the survey design. To this end, a one-day workshop was held on September 19th 2007 in Toronto. Thirty people attended by invitation, including specialist speakers, project staff and those with policy, program planning, and analysis skills to represent regions across Canada (the participants are listed at the end of this report).

NSS2 workshop planning and objectives

The planning committee included representatives from the National Skin Cancer Prevention Committee, co-investigators and collaborators on the NSS2 project, and study staff. The objectives of the workshop were to:

- share basic design features and preliminary descriptive results from the NSS2;
- stimulate discussion of priority areas for national and regional analyses;
- identify ways to translate results into products that would be useful for shaping policy and prevention (reduction of UVR exposure and skin cancer prevention);
- explore methods for disseminating these products to enhance impact on health promotion, planning and surveillance; and
- provide a preliminary base sample data file, as well as hands-on data-analysis training.

To prepare participants, a summary of workshop goals, an overview of the NSS2, and detailed documentation about its content and data files were provided in advance.

Workshop agenda

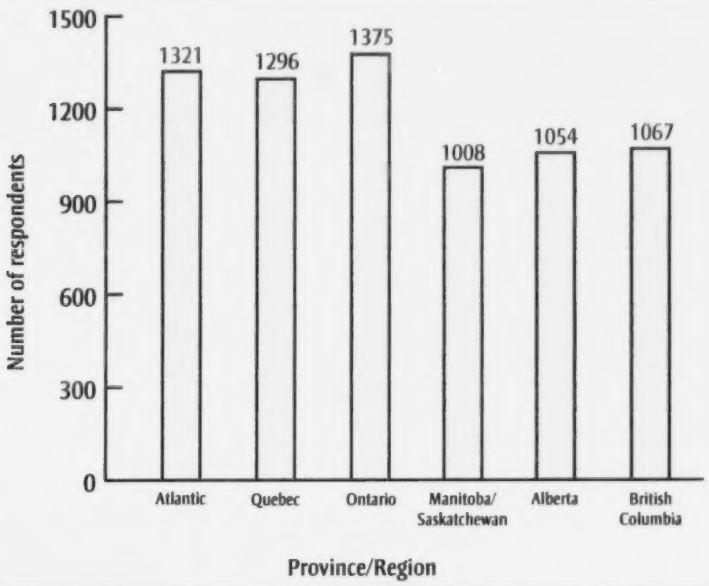
The morning session began with an overview of skin cancer and UVR, NSS2 methods and preliminary base sample results by the NSS2 principal investigator, Dr. Loraine Marrett (Cancer Care Ontario). Figures 1 and 2 demonstrate components of survey design and results. Figure 1 illustrates the number of survey respondents by region: one of the NSS2's strengths lies in its relatively large sample sizes for all regions in order to allow extensive and varied analyses at the national level, as well as a broad selection at the regional level. Figure 2 shows the regional variation depicting the proportion of adults who spent at least 2 hours in the sun on a typical summer day.

Dr. Vitali Fioletov (Environment Canada) then shared the results of estimating the UV index for each respondent's location of

Author References

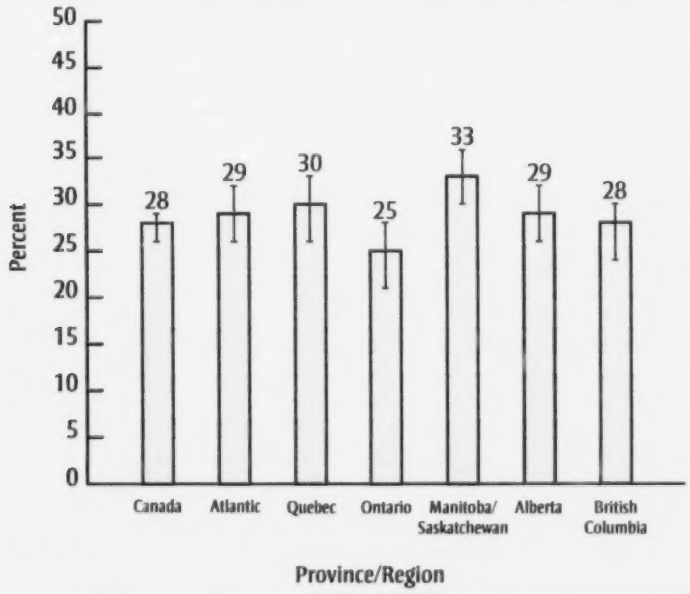
1 Population Studies and Surveillance, Cancer Care Ontario, Toronto, Ontario
2 Department of Public Health Sciences, University of Toronto, Toronto, Ontario
Correspondence: Loraine Marrett, Population Studies and Surveillance, Cancer Care Ontario, University of Toronto, 620 University Ave, Toronto ON M5G 2L7,
Tel.: 416-217-1381, Fax: 416-971-6888, Email: loraine.marrett@cancercare.on.ca
For information on how to access the Second National Sun Survey (NSS2) Public Use Data File, and/or related materials, please email surveillanceunit@cancercare.on.ca

FIGURE 1
Second National Sun Survey (NSS2) sample sizes by province/region, 2006



Atlantic Provinces = New Brunswick, Newfoundland/Labrador, Nova Scotia and Prince Edward Island
Source: Second National Sun Survey, 2006

FIGURE 2[a]
Percent of Canadian adults 16+ who spent at least 2 hours in the sun on a typical summer day by province/region, 2006[b]



[a] This figure is based on a composite measure (weighted average) of two questionnaire items:
a. Amount of time spent in the sun between 11 a.m. and 4 p.m. on a typical **weekday** during June, July and August, and
b. Amount of time spent in the sun between 11 a.m. and 4 p.m. on a typical **weekend day** during June, July and August
Age standardized to the 2001 Canadian population
Σ = 95% confidence intervals
[b] Atlantic Provinces = New Brunswick, Newfoundland/Labrador, Nova Scotia and Prince Edward Island
Source: Second National Sun Survey, 2006

residence during the summer of 2006. These estimates will allow a more comprehensive assessment of individual-level UVR dose, as well as exploration of reported behaviours in relation to climatology. Dr. Scott Leatherdale (Cancer Care Ontario) presented an overview of NSS2 results regarding knowledge, attitudes and beliefs about sun safety.

After lunch, participants split into two groups:

Group 1. NSS2 staff led the 7 data analysts in a hands-on training session covering the following areas:

- basic survey sampling methodology;
- contents of the draft NSS2 Data User Guide, with emphasis on the NSS2 sampling design and computation of weights, calculation of precision indicators (i.e. sampling variance) and data release guidelines;
- structure and contents of the preliminary base sample public use data file; and
- methodology and syntax for generating NSS2 estimates using SAS and SPSS.

Analysts were given the preliminary base sample public use data file on CD. The final base sample public use data file was distributed at a second analyst workshop (held in March 2008) that resulted in part from participants' very positive evaluations of the September 2007 workshop and the expression of a need for further analysis training.

Group 2. The remaining attendees participated in an interactive discussion session designed to provide study staff with some direction around:

- priority UVR protection issues and how the NSS2 could help address them;
- key target audiences for information/reports from the NSS2;
- useful and effective characteristics of reports; and

- methods of ongoing collaboration and communication.

A synopsis of these discussions and main themes is presented in Table 1.

During this session, Dr. Steve Manske (University of Waterloo) provided an overview of knowledge transfer and exchange. He emphasized the importance of relevant, simply-stated information, as well as interaction taking into account all participants' needs, as the main elements for translation of knowledge into action.[4]

Recommendations

The NSS2 Workshop participants provided key advice and recommendations about translation of data into useful products to shape policy and prevention efforts. Many of the participants identified two main issues, namely the importance of forming and delivering messages about sun safety correctly and consistently, and tailoring messages to target groups identified through NSS2 data.

A context discussion elicited the suggestion to examine what kinds of laws and media messages effectively promote behaviour change, both at the system and individual levels. Laws and regulations force people into new behaviours, while social marketing encourages and motivates people to adopt new behaviours by promoting messages and interventions that demonstrate the benefits of these behaviours and how to overcome barriers. A successful example of these two methods of influence working together is tobacco taxation and the denormalization of smoking through social *marketing*.

Participants suggested that reports with short descriptive chapters and simple text summaries of results would be most effective. Peer-reviewed publications could be used for complex analyses involving modeling, while *SunSurv*, a data system designed to provide users with access to NSS2 background documentation and basic descriptive results, will be crucial for generating basic descriptive data by non-analysts. Participants agreed that the NSS2 data could play a key role in motivating sun behaviour change through translating data into useable material for policy-makers, ultimately to aid in the prevention of skin cancer.

TABLE 1

Sun safety issues and recommendations from the Second National Sun Survey Workshop

Issues identified	**Priorities for UVR safety**	**Artificial tanning equipment and increase in use, legislation issues**
		Accurate messages regarding Vitamin D
		Target groups such as outdoor workers and youth
		Key and consistent messaging around sun safety
	How the NSS2 can address the priorities	**Descriptive analyses of target groups**
		Identification of those who seek the sun/ do not protect themselves
		Examine beliefs about and use of tanning equipment
		Identification of further data-collection opportunities
		Use the above to create/change messages
Context for implementation	**Key stakeholders**	**Public and regional health units, other organizations with sun safety as a focus**
	Target audiences	**Children (through pediatricians, schools, parents), young adults, shade planners, media, parks and recreation, outdoor worker employers**
	Means of engaging	**Form community of practice (stakeholder organization)**
		Examine what has worked – tobacco strategies
		Sell the relevance through media
Recommended outputs from the NSS2	**Simple text summaries of results – fact-sheet style**	
	Peer-reviewed publications with complex analysis/modeling	

Acknowledgements

This NSS2 workshop was funded by the Canadian Cancer Society (National and Ontario Divisions) as well as the Public Health Agency of Canada. The principal investigator for the NSS2 is Dr. Loraine Marrett, and co-investigators are Dr. Cheryl Rosen, Dr. Joel Claveau, Dr. Marc Rhainds, David Northrup, and Jennifer Fergenbaum.

The authors would also like to acknowledge the assistance of the National Skin Cancer Prevention Committee, whose members acted in a steering capacity, and the Institute for Social Research (York University), as well as Jolie-Coeur and Associates (Quebec) for administering the survey.

Michael Spinks (South East Local Health Integration Network; Cancer Care Ontario) provided invaluable guidance for analysis planning, and structuring and facilitating the workshop analysis session. Yen Borrego, Sandrene Chin Cheong and Greg Kennedy of Cancer Care Ontario are also acknowledged for their support around workshop planning, data management and analysis, and preparation of graphical materials.

Workshop participants

Riaz Alvi (Saskatchewan Cancer Agency), Rosemary Boyle (Canadian Cancer Society, New Brunswick Division), Doreen Callander (Canadian Cancer Society, Saskatchewan Division), Heather Chappell (Canadian Cancer Society), Christina Chociolko (National Collaborating Centre for Environmental Health), Vitali Fioletov (Environment Canada), Lynn From (Women's College Hospital), Irene Gallagher (Canadian Cancer Society, Ontario Division), Suzanne Gingras (Institut national de santé publique du Québec), Jane Griffith (Cancer Care Manitoba), ***Scott Leatherdale** (Cancer Care Ontario), Tim Lee (BC Cancer Research Centre), Sylvia Leonard (Canadian Cancer Society, Ontario Division), ***Steve Manske** (University of Waterloo), ***Loraine Marrett** (Cancer Care Ontario), ***David Northrup** (Institute for Social Research), Corinne Parker (Alberta Cancer Board), ***Erin Pichora** (Cancer Care Ontario), ***Judy Purcell** (Cancer Care Nova Scotia), Steven Quantz (Alberta Cancer Board), Pascale Reinhardt (Health Canada), ***Marc Rhainds** (Institut national de santé publique du Québec), ***Cheryl Rosen** (Toronto Western Hospital), Holly Smith (Canadian Cancer Society, PEI Division), ***Michael Spinks** (South East Local Health Integration Network and Cancer Care Ontario), Sharon Storoschuk (Canadian Cancer Society, BC and Yukon Division), ***Bronwen Waller** (Cancer Care Ontario), Gordon Walsh (Cancer Care Nova Scotia), Lin Xue (Cancer Care Manitoba).

***Member of workshop planning committee/ NSS2 staff/co-investigators**

References

1. Canadian Cancer Society/National Cancer Institute of Canada. Canadian Cancer Statistics. Toronto: Canadian Cancer Society/ National Cancer Institute of Canada, 2008.

2. Lovato C, Shoveller J, Rivers J (eds). Final Report: National Survey on Sun Exposure and Protective Behaviours. Institute of Health Promotion Research: University of British Columbia, 1997.

3. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: time for a map? J Contin Educ Health Prof. 2006;26(1):13-24.

Announcements

Our Principal Scientific Editor at the Journées annuelles de santé publique

Dr. Sylvie Stachenko, Deputy Chief Public Health Officer and Principal Scientific Editor of *Chronic Diseases in Canada*, will participate in the opening plenary panel of the International Francophone Meeting on Social Inequalities in Health on Monday, November 17, 2008. This meeting kicks off the Journées annuelles de santé publique in Quebec City.

Dr. Stachenko, whose presentation is entitled "Social Inequalities: Perspectives, Issues and Recent Developments," will discuss the significance of the WHO Commission on Social Determinants of Health and its contribution to policy action globally and in Canada. She will highlight recent parallel developments in Canada, including the release of the Chief Public Health Officer's Report on the State of Public Health in Canada, the work of the Senate Subcommittee on Population Health and the Canadian Reference Group on Social Determinants of Health. She will conclude with reflections on the ongoing role of health promotion in advancing action on determinants of health and health inequalities.

WORKSHOP PARTICIPANTS NEEDED: "Is Prevention Better than Cure?"

Background

In 2004, Laurie Goldsmith, Brian Hutchison and Jeremiah Hurley published "Economic Evaluation Across the Four Faces of Prevention: A Canadian Perspective." This paper, commissioned by the Canadian Medical Association, aimed to create an updated review of economic evaluation evidence on prevention to assist in priority-setting in the Canadian context.

The National Collaborating Centre for Healthy Public Policy (NCCHPP) recently published a French translation of the paper to make it available to a larger audience and to expand the base of actors who may participate in pan-Canadian workshops.

To read the paper in English, please go to the following link: http://www.evaluationcanada.ca/distribution/200405_goldsmith_laurie_hutchison_brian_hurley_jeremiah.pdf.

To read the paper in French, please go to the following link: http://www.ccnpps.ca/docs/FR-EvaluationEconomique.pdf.

PAN-CANADIAN WORKSHOPS

In collaboration with Laurie Goldsmith of Simon Fraser University, the NCCHPP is organizing workshops to update the healthy public policy sections of the 2004 report.

If you wish to participate in this activity or if you want more information, please contact the NCCHPP at ncchpp@inspq.qc.ca.

CDIC: Information for Authors

Chronic Diseases in Canada (CDIC) is a quarterly scientific journal focussing on the prevention and control of non-communicable diseases and injuries in Canada. Its feature articles are peer reviewed. The content of articles may include research from such fields as epidemiology, public/community health, biostatistics, the behavioural sciences, and health services or economics. CDIC endeavours to foster communication on chronic diseases and injuries among public health practitioners, epidemiologists and researchers, health policy planners and health educators. Submissions are selected based on scientific quality, public health relevance, clarity, conciseness and technical accuracy. Although CDIC is a publication of the Public Health Agency of Canada, contributions are welcomed from both the public and private sectors. Authors retain responsibility for the contents of their papers, and opinions expressed are not necessarily those of the CDIC editorial committee nor of the Public Health Agency of Canada.

Article Types

Peer-reviewed Feature Article: Maximum 4,000 words for main text body (excluding abstract, tables, figures, references) in the form of original research, surveillance reports, meta-analyses or methodological papers.

Status Report: Describe ongoing national programs, studies or information systems bearing on Canadian public health (maximum 3,000 words). Abstract not required.

Workshop/Conference Report: Summarize significant, recently held events relating to national public health (maximum 1,200 words). Abstract not required.

Cross-Canada Forum: For authors to present or exchange information and opinions on regional or national surveillance findings, programs under development or public health policy initiatives (maximum 3,000 words). Abstract not required.

Letter to the Editor: Comments on articles recently published in CDIC will be considered for publication (maximum 500 words). Abstract not required.

Book/Software Review: Usually solicited by the editors (500B1,300 words), but requests to review are welcomed. Abstract not required.

Submitting Manuscripts

Submit manuscripts to the Editor-in-Chief, Chronic Diseases in Canada, Public Health Agency of Canada 130 Colonnade Road, Address Locator: 6501G, Ottawa, Ontario K1A 0K9, e-mail: cdic-mcc@phac-aspc.gc.ca.

Since CDIC adheres in general (section on illustrations not applicable) to the **"Uniform Requirements for Manuscripts Submitted to Biomedical Journals"** as approved by the International Committee of Medical Journal Editors, authors should refer to this document for complete details before submitting a manuscript to CDIC (see < **www.icmje.org** > .

Checklist for Submitting Manuscripts

Cover letter: Signed by all authors, stating that all have seen and approved the final manuscript and have met the authorship including a full statement regarding any prior or duplicate publication or submission for publication.

First title page: Concise title; full names of all authors and institutional affiliations; name, postal and e-mail addresses, telephone and fax numbers for corresponding author; separate word counts for abstract and text.

Second title page: Title only; start page numbering here as page 1.

Abstract: Unstructured (one paragraph, no headings), maximum 175 words (100 for short reports); include 3B8 key words (preferably from the Medical Subject Headings (MeSH) of Index Medicus).

Text: Double-spaced, 1 inch (25 mm) margins, 12 point font size.

Acknowledgements: Include disclosure of financial and material support in acknowledgements; if anyone is credited in acknowledgements with substantive scientific contributions, authors should state in cover letter that they have obtained written permission.

References: In AVancouver style@ (consult a recent CDIC issue for examples); numbered in superscript in the order cited in text, tables and figures; listing up to six authors (first three and Aet al.@ if more); without any automatic reference numbering feature used in word processing; any unpublished observations/data or personal communications used (discouraged) to be cited in the text in parentheses (authors responsible for obtaining written permission); authors are responsible for verifying accuracy of references.

Tables and Figures: Send vector graphics only. Each on a separate page and in electronic file(s) separate from the text (not imported into the text body); as self-explanatory and succinct as possible; not too numerous; numbered in the order that they are mentioned in the text; explanatory material for tables in footnotes, identified by lower-case superscript letters in alphabetical order; figures limited to graphs or flow charts/templates (no photographs), with software used specified and titles/footnotes on a separate page.

Number of copies: If submitting by mail, one complete copy, including tables and figures; one copy of any related supplementary material, and a copy of the manuscript on diskette. If submitting by e-mail to cdic-mcc@phac-aspc.gc.ca, please fax or mail the covering letter to the address on the inside front cover.